David N. Weisstub
Guillermo Diaz Pintos

International Library of Ethics, Law, and the New Medicine 36

Autonomy and Human Rights in Health Care

An International Perspective

Springer

AUTONOMY AND HUMAN RIGHTS IN HEALTH CARE

INTERNATIONAL LIBRARY OF ETHICS, LAW, AND THE NEW MEDICINE

VOLUME 36

The titles published in this series are listed at the end of this volume.

Autonomy and Human Rights in Health Care

An International Perspective

Edited by

DAVID N. WEISSTUB
Université de Montréal,
QC, Canada

GUILLERMO DÍAZ PINTOS
Universidad de Castilla-La Mancha,
Ciudad Real, Spain

UCLM
UNIVERSIDAD DE CASTILLA-LA MANCHA

Springer

A C.I.P. Catalogue record for this book is available from the Library of Congress.

ISBN 978-1-4020-5840-0 (HB)
ISBN 978-1-4020-5841-7 (e-book)

Published by Springer,
P.O. Box 17, 3300 AA Dordrecht, The Netherlands.

www.springer.com

Printed on acid-free paper

CONTENTS

Preface ix
EDMUND D. PELLEGRINO

Contributors xiii

Introduction 1
GUILLERMO DÍAZ PINTOS AND DAVID N. WEISSTUB

PART I: HEALTH CARE, HUMAN RIGHTS AND SOCIAL POLICY

1. Evolving Bioethics and International Human Rights 11
DAVID C. THOMASMA

2. Dignity, Rights, Health Care, and Human Flourishing 25
DAVID P. SULMASY

3. Human Rights: The Ethics of Globalization 37
GUILLERMO DÍAZ PINTOS

4. Human Rights and the Right to Health Care 45
AMNON GOLDWORTH

5. Religion, International Human Rights and Women's Health: Synthesizing Principles and Politics 55
DAVID E. GUINN

PART II: THE CENTRALITY AND LIMITS OF AUTONOMY

6. The Limitations and Accomplishments of Autonomy as a Basic Principle in Bioethics and Biolaw 75
JACOB D. RENDTORFF

7. Person and Human Being in Bioethics and Biolaw 89
LAURA PALAZZANI

8. Welfare Rights and Health Care 99
JUAN RAMÓN DE PÁRAMO ARGÜELLES

9. Autonomy and the Rights of Minors 111
WAYNE VAUGHT

10 Domestic Violence 123
GEORGE P. PALERMO

11. Balancing Autonomy and Traditional Values in Treating Terminally Ill Patients: Towards Locating the Right Questions for Japan 143
DAVID N. WEISSTUB

PART III: PLURALISM, RACE AND HEALTH

12. Culture, Community or Rights 155
TERRY CARNEY

13. Bioethics Between Nature and Culture 173
ANA MARTA GONZÁLEZ

14. Medical Practice as the Primary Context for Medical Ethics 189
HENK JOCHEMSEN

15. Euthanasia and Multiculturalism 205
ANDRÉS OLLERO

PART IV: FUTURE LEGAL ORDERING AND SOCIAL PLANNING

16. International Law and Genetic Counselling 217
CARLOS M. ROMEO-CASABONA

17. International Perspective on Organ Donation 235
ELISA J. GORDON

18. Justice in the Distribution of Transplant Organs 257
ROSAMOND RHODES

19. Human Cloning and Human Dignity 271
ÁNGELA APARISI MIRALLES AND JOSÉ LÓPEZ GUZMÁN

20. Accessing Health Care Resources: Economic, Medical, Ethical and Socio-Legal Challenges 291
GEORGE P. SMITH, II

21. Mental Health Rights: The Relation between Constitution and Bioethics 309
JULIO ARBOLEDA-FLÓREZ AND DAVID N. WEISSTUB

PART V: INDIVIDUAL INTEGRITY, RESEARCH ETHICS AND HUMAN RIGHTS

22. The "Vulnerability" Quagmire in International Research 331
JUDITH KISSELL

23. Human Rights, Health Care and Biomedical Innovation: Confronting the Research Imperative 341
GEORGE F. TOMOSSY

24. The Rights to Die and the Duty to Save: A Reflection on Ethical Presuppositions in Suicide Research 353
BRIAN MISHARA AND DAVID N.WEISSTUB

25. The Right to Bodily Security vis-à-vis the Needs of Others 375
AUSTEN GARWOOD-GOWERS

Index 399

PREFACE

EDMUND D. PELLEGRINO

David C. Thomasma—In Memoriam

For a Friend and Teacher

Rejoice you dead, wher'er your spirits dwell

Rejoice that yet on Earth your fame is bright.

Robert Bridges, Ode to Music

1844–1930

It has often been said that we really die only when we are forgotten. If there is any truth in these words, David Thomasma will live for a long time in the memories of his professional colleagues world-wide. We need not ask whether the man or his work will live longer, as William Osler did in his Preface to the life of Louis Pasteur (Vallery-Radat 1928). In David Thomasma, the man and his work, his mind and his heart were inseparable.

They were an amalgam in which one blended imperceptibly into the other.

David was a rarity, a humanist philosopher whose critical intelligence was always modulated by his humanity. His benevolence for his fellow humans was not that of the sophisticate who loves the species but abhors the man. David always closed the distance between himself and his students or colleagues to engage hearts as well as minds.

The springhouse of his intellect was amply fed from the vast reservoir of the works of Aristotle and Aquinas. From Aristotle he imbibed a taste for an orderly perspective on the real world and a respect for its openness to human reason. From Thomas David imbibed the enrichment of reason by faith, and the intellectual humility to see whatever portion of truth was latent in the thought of others. This was especially true of the modern philosophers he studied with equal passion.

David was an omnivorous reader, a polymath who eschewed pontification but convinced by the depth and incisiveness of his knowledge. His knowledge ranged well beyond philosophy and ethics to embrace the sports pages, the public media, contemporary music and the latest gossip circulating in the bioethics community. Language and social barriers could not contain his energetic pursuit of knowledge. That pursuit was always conducted with geniality, humor and obvious good will.

David was superbly equipped to be a collaborator in all sorts of scholarly endeavors. He co-authored books and papers with half a dozen different colleagues from within and outside philosophy. Some were physicians, some social scientists and others were European scholars with whom he was working to establish better international understandings of bioethics. Indeed collaboration and cooperation were David's forte. David was a pioneer in the meetings he sponsored in Europe bringing scholars from Europe and America into effective communication with each other. Those meetings will be remembered as much for their conviviality as their intellectual substance. David emerged as our Benjamin Franklin, an ambassador without portfolio for American bioethics, spreading erudition, with American practicality and personal diplomatic aplomb.

I had the extraordinary privilege of enjoying David's gifts as a collaborator for two decades. During that time we produced five books, and more than half dozen articles. We were working on a revision of our major work – A Philosophical Basis of Medical Practice – when he died unexpectedly. Nothing could convince me more of his irreplacability in our joint works than my efforts since his death to complete the task of revision. No small part of my problem has been asking myself about each change in the text – "Would David approve?"

During our collaboration I can remember no instance of serious disagreement. A good part of this was related to the similarity of our intellectual formations and interests. David and I both majored in chemistry and still felt ourselves disposed, in the spirit of Albertus Magnus, to experimental science as well as philosophy. We were likewise formed in the tradition of Fides et Ratio, of the compatibility, necessity and mutual enrichment of medicine by theology and philosophy. Our conclusions were sometimes rejected because of our refusal to see incommensurability in the relations of science and theology. All too often we had to chide our critics and ask them to deal with our reasoning and conclusions and not with the fact that they might be compatible with religion.

Our writing sessions were sources of the greatest pleasure to me. David sat at his computer; I sat at my old mechanical Olivetti typewriter. Each would write a draft which the other would edit and criticize mercilessly. After many passages back and forth, we would agree and move on. We both wrote with classical music in the background. David's tastes were far more cosmopolitan than mine however.

Our writing styles were different and some critics claim to know who wrote what. However the case may be I cannot tell even now how much of any passage was David's and how much mine – except that David's words were more concrete than mine. Our love for Latin and Greek came through here and there and had to be curtailed since our memories of these languages often had to be refurbished. David's familiarity with German and Dutch gave us access to some of the best Europe was producing at the time.

Thomasma enjoyed debates, whether the subject was moral philosophy, the relative merits of competing sports teams or justice in the health care system. He interlaced his debates with choice stories, practical jokes and insight. His conclusions were always clear, tempered by his signature combination of moral insight and compassion.

It was easy to see David as the jolly friar, with cincture around his ample rotundity. He filled his discourses with humor, but motivating him always were the same vocation to healing, helping, counseling and comforting that led him to enter the Dominican Order. After he was laicized, he remained a Dominican friar in spirit, no longer in the confessional but transposed to the classroom, the podium or the bedside.

David's published works touched almost every important subject in the bioethics of his time. We shared a major enterprise together – the elaboration of a philosophy of medicine upon which a moral philosophy and an ethics of medicine-clinical-basic and social could be erected. Our long term plans called for linking these elements to a philosophical and theological anthropology. We were foundationalists without apology, convinced of the validity of a philosophia perennis, and aware of the need for integrating these philosophical perspectives with the emerging facts of experimental science.

In a time of analytic philosophy, and post modern skepticism, David held fast to the spirit of classical and medieval philosophy but opened his mind as well to the insights of the Moderns. He appreciated Merleau Ponty, Husserl, Gadamer, and Habermas. We will never know what plans he might have had for a better synthesis of new and old.

What is incontrovertibly true is that David Thomasma touched so many hearts, in Europe as well as America, that the flame of his memory will keep him alive for many years.

More life went out when he left than ordinary breath (Dickinson 1960).

REFERENCES

Vallery-Radat, R. (1928). *The Life of Pasteur.* New York: Doubleday and Co.
Dickinson, E. (1960). *The Complete Poems of Emily Dickinson.* Boston: Little Brown.

CONTRIBUTORS

Julio Arboleda-Flórez
Department of Forensic Psychiatry
Queen's University
Kingston, Canada

Terry Carney
Faculty of Law
The University of Sydney
Sydney, Australia

Austen Garwood-Gowers
Law School
Nottingham Trent University
Nottingham, UK

Amnon Goldworth
Department of Paediatrics
Stanford School of Medicine
Stanford, CA, USA

Ana Marta González
Faculty of Philosophy
University of Navarra
Navarra, Spain

Elisa J. Gordon
Neiswanger Institute for Bioethics
and Health Policy
Loyola University Medical Center
Maywood, IL, USA

David E. Guinn
Health Law Institute
DePaul University
Chicago, IL, USA

José López Guzmán
Faculty of Medicine
University of Navarra
Navarra, Spain

Henk Jochemsen
G.A. Lindeboom Institute
Centre for Medical Ethics
Ede, The Netherlands

Judith Kissell
Center for Health Policy and Ethics
Creighton University Medical
Center
Omaha, NE, USA

Ángela Aparisi Miralles
Faculty of Law
University of Navarra
Navarra, Spain

Brian Mishara
Department of Psychology
Univeristy of Quebec at Montreal
(UQAM)
Montreal, QC, Canada

Andrés Ollero
Faculty of Law
University Juan Carlos I
Madrid, Spain

George P. Palermo
Department of Psychiatry and
Neurology
Medical College of Wisconsin
Milwaukee, MI, USA

Guillermo Díaz Pintos
Faculty of Law and Social Sciences
University of Castilla-La Mancha
Ciudad Real, Spain

Carlos M. Romeo-Casabona
Faculty of Law
University of Deusto
Bilbao, Spain

David C. Thomasma
Neiswanger Institute for Bioethics
and Health Policy
Loyola University Medical Center
Maywood, IL, USA

David N. Weisstub
Faculty of Medicine
University of Montreal,
Montreal, QC, Canada

Laura Palazzani
Faculty of Jurisprudence
Free University of Maria
SS.Assunta
Rome, Italy

Juan Ramón de Páramo Argüelles
Faculty of Law and Social Sciences
University of Castilla-La Mancha
Ciudad Real, Spain

Rosamond Rhodes
Department of Medical Education
Mount Sinai School of Medicine
New York, NY, USA

George P. Smith, II
Professor of Law
Catholic University of America
Washington, D.C.

Daniel P. Sulmasy
The Bioethics Institute of New York
Medical College
St. Vincent's Hospital
New York, NY, USA

George F. Tomossy
Division of Law,
Macquarie University
Sydney, NSW, Australia

GUILLERMO DÍAZ PINTOS AND DAVID N. WEISSTUB

INTRODUCTION

The essays contained in this volume are an homage to the life and work of David C. Thomasma whose essay "Evolving Bioethics and International Human Rights" is posthumously printed here. Professor Thomasma did the essential work to evolve this volume. His colleagues, within the international community related to his voluminous publications and collegial relations over a span of many decades, have written works contained here that have attempted to grapple with Professor Thomasma's major intellectual concerns. It is no accident that his last efforts addressed the pressing questions with which he was preoccupied, namely how to wed human rights as understood by a pluralism of cultures to a moral compass of significant universal dimensions. The solution for David Thomasma was to found and develop an intercultural communitarian ethics in order to rejuvenate bioethics as a corrective to the autonomy-based North American perspective that had come to dominate recent thinking. In David's perspective any idea of human rights for bioethics had to find its natural resting place between community and nature. He was firmly of the view that bioethics was impossible without a thorough understanding of the entitlements of economic and social rights. In so doing Professor Thomasma's reflections were consonant with progressive orientations found in constitutional law in many jurisdictions. In his essay he proposes a thought provoking assembly of procedural and substantive rules to form the basis of what he called "an international, multicultural bioethics".

David Thomasma wrote elaborately on the question of human dignity and vulnerability. It is timely therefore to have contained in this volume an essay by his longstanding colleague, Daniel Sulmasy. He provides an in-depth reflection on dignity and its relationship to healthcare. Sulmasy asserts that dignity is prior to rights. For him dignity refers both to intrinsic dignity (the value a human being has by virtue of being the kind of thing he or she is) and attributed dignity (the value someone has by virtue of human attribution). Universal human rights are based on intrinsic dignity, and local, stipulative rights are based upon attributed dignity. A right to healthcare is recognized as a local, stipulative right. To the extent that resources are available to societies they are obligated to provide healthcare.

One of the central themes that infused David Thomasma's latter publications was the imposing phenomenon of globalization. In his chapter on the ethics of globalization Guillermo Díaz Pintos confronts the issue of how pluralism can remain compatible with a just bioethics. He argues in favor of a position that maintains that the new social practices which began in modernity with the presence of natural rights, thereafter having evolved into our contemporary understanding of human rights, refer to indispensable values that facilitate communication and dialogue

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 1–7.

within the reality of moral pluralism. In the praxis of rights as we know them, Guillermo Díaz Pintos searches for a definition of justice which can still persist at the base of social good and collective values. Related to this is the identity of all subjects who participate actively or passively in the exercise of human rights. Finally, Prof. Pintos searches for how duty requires the establishment of an order for human life, in a world in which technique has eliminated the inherent necessity of a "natural order", which previously provided the foundation for ethics.

The work of Amnon Goldworth is a highly original text providing an analysis of human rights and squarely addresses the question "What does it mean to say a person has a human right?" His theory is based on his social contract perspective with specific reference to the notion of adequate compensation. He argues that the human right to health care is based upon a theory of human rights and concludes that the concept of human rights supports the claim that there is a human right to health care.

David E. Guinn deals with the practical question of how to deal with the conflict when notions of human rights are set upon by religious values and traditional cultures. He argues against absolutist understanding of rights and strict equality standards of interpretation in favor of "substantive equality". While a principled interpretation of rights can be seen to provide some guidance, ultimately its utility is seen to be limited. Guinn insists that it is imperative to consider rights within their political context. His essay, which concentrates on the highly controversial example of female circumcision, points out that it is not productive to determine how rights take precedence over each other, but rather to search for a respectful synthesis of rights and how they relate to one another in context.

David Thomasma saw autonomy as being central to the proper protection of human rights and healthcare. Increasingly however, he was convinced that it was only in a full and complete understanding of its limitations that bioethics and biolaw could address the full range of issues that he and others were confronting in clinical practice. The chapter by Jacob D. Rendtorff examines the history of the concept of autonomy and its political notion in order to effectively deal with its limitations in relation to the "encounter" as it occurs between physicians and patients. His work can be seen as a complement to the published works of David Thomasma on this question. It explores how the principle of autonomy should be combined with the protection of human dignity, integrity, and vulnerability – to successfully respond to how human rights can be properly linked to bioethics and biolaw.

Laura Palazzani, in addressing the problem of dignity and its relationship to rights indicates that there are philosophical ambiguities pertaining to the relationship between dignity and rights that reveal opposing trends in bioethics: "personism" which relies upon the centrality of the concept of person where the concept of the person is distinctive from that of a human being (reducing the range of application of a person to human beings while at the same time extending it to non-humans), and "personalism" which claims an intrinsic identity between person, human being, and human life and can be connected to the mainstream of western philosophical speculation. For Laura Palazzani it is imperative that an ontological foundation of the concept of person be established in order to protect human life and its relation to personhood throughout the life cycle.

The work of Juan Ramón de Páramo Argüelles addresses the crisis of the welfare state, using Spain as an example. Arguably there is a general loss of confidence in welfare state systems throughout the globe, nowhere so severely felt as in the instance of healthcare. De Paramo Argüeles discusses the concept of welfare rights, making special reference to the right to health care, the contradictory nature of which highlights the doubts and disagreements over the limits of welfare spending, in particular on public health care. His position is that considerable increases in welfare spending will be required necessitating larger taxes and the incurring of deficits. Societies must deal with the reality that ‘zero deficits’ and the ‘lowering of taxes’ will not resolve the inevitable burdens of deficits in welfare programs and health entitlements. Extreme forms of liberalism cannot be reconciled with incentives to find a collective solution to the gap between revenues and resources. The conflict engendered by this tension between autonomy and collectivity goes to the heart of the future of healthcare and its relationship to rights.

The role of minors and their emancipation highlights a critical practical field within healthcare decision-making. Wayne Vaught argues that health professionals have a *prime facie* moral obligation to respect the wishes of minors when they have developed relevant capacities. He deals with a series of challenges that have been made to the authority of adolescent decision makers, such as the need to protect minors from negative impacts on their future and the centrality of the family in health care decision-making. The essay argues that adolescents’ rights to make treatment decisions increase, along with their developing decisional capacities.

One of the most pressing contemporary problems worldwide is that despite decades of apparent improvements in gender related issues of healthcare there are a host of difficulties remaining which can be seen in crystallized form within the cycles of domestic violence. George Palermo offers a typology of victims and victimizers. He points out that domestic violence, whether physical or sexual, reflects a clash between autonomy and control among family members. He sees the quest for excessive autonomy as the facilitator of a disharmonious imbalance among family members, contributing to resentful, hostile and abusive behavior by those members (usually husbands or male cohabitants) who, because of characterological or serious emotional dysfunctions, are already predisposed to react in an antisocial morally unacceptable manner. He concludes that the tragedy of domestic violence can only be overcome by reaching a judicious interpersonal balance in the realization of autonomy within the family construct.

Eastern and western values are frequently demonstrated as being exemplary but fundamentally divergent points of view on the issue of autonomy. David N. Weisstub points out that in dealing with life and death decisions in Japan with respect to the terminally ill there is a ripe testing ground to reflect on supposed or actual cultural and theoretical differences. A series of questions are posited about definitional issues, theoretical foundations, competency, decision making models, state intervention, and the significance of epidemiological findings.

In the section on Pluralism, Race and Health, Terry Carney contrasts autonomy with relational rights that reflect the social dimension of citizenship. Utilizing central elements in health law such as guardianship Carney seeks novel directions for how law can foster “positive/developmental” rights formerly secured through the welfare state. The crisis for autonomy and health entitlements can be found in privatization forces which have fractured social reciprocity. Communitarian and contractual models are argued to have utility in addressing this crisis but Carney also enlists the support of such measures as tribunals and other “popular” justice institutions as mechanisms to redress recent value imbalances.

Ana Marta González returns to the rudiments of natural law theory as the appropriate method for discovering an ethical rationality as the vehicle for making healthcare decisions in multicultural societies. Minimalist ethics have resulted in promoting specific cultures which create a certain way of looking at the relation between the private and public realm. This has not managed to react to the deeper connection between nature and culture and the unity of practical reason. It is Ana Marta González’s view that it is only in the revitalization of natural law theory that bioethics can avoid contemporary impasses and be ethically viable.

The contribution of Henk Jochemsen finds the resolution of how to ground bioethics in actual medical practice through the elucidation of a specific normative structure. Jochemsen claims that this normative structure can be acknowledged as independent of any world view while at the same time maintaining that actual practice is always co-informed by notions of life, health and death that are partly dependent on world view and religion.

Andrés Ollero treats the polemic ridden issue of euthanasia from the point of view of anthropological and religious discrepancies found within current multicultural frameworks. He asserts that only if we base ourselves on objective principles when deciding which culturally alien elements to include in an ethical minimum to be enforced by law will we be able to avoid the exclusion which frequently underlies multicultural coexistence.

The section on Future Legal Ordering and Social Planning looks at a range of topics where legal ethics and bioethics have an ongoing interplay. Carlos Romeo-Casabona offers a comprehensive review of the range of genetic tests currently under use and the international overseeing guidelines that are affecting bioethics decision making. Because these tests have an inevitable massive impact on healthcare distribution, fundamental ethical questions about entitlements, not only with respect to the tests themselves, but in relationship to offspring, cannot be avoided. Romeo-Casabona’s contribution looks at various models of governance affecting reproductive decision making and the ethical sensitivities required of genetic counselors working in health systems.

From an anthropological perspective Elisa Gordon explores the reasons for variation in organ donation practices and the reasons why respect for individual autonomy is frequently not taken into account in cadaveric donation. The author reviews the spectrum of cultural diversity pertaining to organ donations and divergent responses to legal policies whose intention it was to increase organ donation rates. Gordon’s opinion is that it is essential to have an international overview in order to increase organ donation at various levels of government. It can readily be seen that organ donation, rife with ethically sensitive components, has concrete and significant consequences for health care.

In the continuation of the organ transplant theme, the chapter by Rosamond Rhodes approaches the topic from a rigorous analysis of theories about just allocation. She maintains that the only considerations that are relevant to clinical justice can be reduced to need, urgency and efficacy. In dealing with organ transplants she insists that only factors of clinical justice can be justifiably taken into account. Matters of personal history such as social standing and geography or nuances with respect to worthiness should have no role to play in organ allocation. Rhodes applies her standards of clinical justice to existing policies, identifying how certain positions are not properly supported by data and continue to reflect prejudice and political considerations. Rhodes demonstrates that there are considerable discriminatory practices extant and that geographical considerations continue, without ethical justification, to govern policies in the transplant area.

Human cloning is at the forefront of crossing the threshold of new health care claims. Ángela Aparisi Miralles and José López Guzmán address the rights of researchers, and their autonomy in relation to basic notions of human dignity and their application to forms of life. The chapter explores the ethical distinctions between cloning for research purposes and cloning tissues for organ transplantation. The chapter also looks at the ethical risks of reawakening the discourses associated with eugenics.

George Smith addresses the extent to which traditional medical ethics is at risk of being distorted and dominated by indiscriminate market forces. He views access to healthcare resources as a matter of grave international magnitude. Societies are, according to his critique, redesigning the concepts of social goods and economic needs through philosophies that are resulting in the rationing of medical goods and services. It will be impossible to resolve these complexities and tensions without further defenses being made about the relation between distributive justice and sound medical practice.

Mental health care is often regarded as the low-end recipient in the culture of downsizing healthcare resources. Yet perhaps more than any other area of medicine there are visible social impacts, ranging from homelessness to the incarceration of mentally ill populations. Julio Arboleda-Flórez and David N. Weisstub explore the manner in which constitutional debates, using Canada as a case example, have been struggling with the creation of a rights based legal culture in order to strengthen the claims against healthcare systems made by mentally ill patients and their families. Despite serious resistance in national policies, both legislative and judicial, there have been movements in international law in the design of principles and guidelines to encourage the amelioration of disturbing trends in denying health care access to mentally ill persons and the disabled. This chapter reveals a guarded measure of optimism from a Canadian perspective, showing that real possibilities do exist within the Canadian constitutional configuration to substantiate health care rights.

In the final section on Individual Integrity, Research Ethics and Human Rights, George Tomossy promotes fidelity to human subject protection. He explores the scope of the societal justification for research. In recognition of the growing relevance of commercial interests in research, he argues for a need to move beyond the classic paradigm of a conflict between the interests of society and subjects. He also debunks the dominant societal justification for research involving human subjects: the research imperative. The goal to advance knowledge about biomedicine and advance human health and longevity should not be accorded the status it currently enjoys. Tomossy concludes that research needs to be properly characterized as a melioristic goal, a societal desire, which merits promotion but not at the expense of the fundamental rights of individual subjects.

Judith Lee Kissell addresses the operations of pharmaceutical companies in overseas drug trials. In her view there is an overwhelming crisis in world-wide justice in health care related to the conducting of drug trials in developing economies. The chapter delves into how a new social class is underway. Her claim is that ethicists thus far have been reluctant to deal with their own role in fashioning standards of obligation for pharmaceutical companies to provide continuing services to societies from which they have been extracting and exporting health care benefits. In conducting clinical trials pharmaceutical companies can be seen to be creating reliances through their undertakings which require immediate ethical analysis and social redress.

Suicide directly or indirectly is related to a myriad of health issues. The decision to end one's life is not only a significant question of human rights, but is inextricably bound to a health context, physical or mental. Epidemiological health data points out connectors, although oftentimes not conclusive or predictive, to families or groups, raising important social policy issues. Because of the multitude of factors that enter into a broadly-conceived social picture of suicide, factors of economy and prioritization lie at the root of health policy. In this light, suicide should be seen as a major component in the field of health rights, both from individual and collective points of view.

A central focus of David Thomasma's life work was on the value of human life and the protection of the dignity of vulnerable populations. In his extensive works, the plight of individual suffering was always highlighted. Without the insistence of an imperial set of values, he never kept the aim far from his work of conceiving an enlightened medical system where the restoration of health based on a respect for personhood could be sustained. Within such a perspective, suicide research should never be disconnected from our core commitments within a liberal democracy to protect vulnerability while preserving the right to choose one's quality of life.

The Mishara – Weisstub essay directs its attention to the ways in which sensitizing researchers to their ethical commitments can eliminate how they should endeavor to treat options in the conduct of their research projects. Inasmuch as concepts about health are value-laden, it can be argued that even more so, "suicide" is packed with ethically charged contexts from which researchers are not absolved. On the contrary, suicide research represents a central topic within the overlapping circumferences of human rights and health care.

In the final chapter of the volume, Austen Garwood-Gowers treats the basic question of the integrity of bodily security against the needs of others. Because the use of the body in medical research has become paramount in light of both research and transplantation the discourses in medical practice and in law have been dramatically implicated. Garwood-Gowers believes that there are restrictive positions being placed on the human body and that the very concept of death is being redefined, placing respect for individual bodily integrity in full jeopardy. The author suggests that not only are these conceptions unconvincing but that there is an a priori interest of persons in the property of their own bodies which guarantees overriding entitlements.

It can be foreseen in light of the chapters in this dedication volume, that controversies about human dignity and healthcare will be re-focused in forthcoming decades as we continue to link revolutionary technology to changing social values and historic, perennial philosophical standpoints. The enormous legacy of David Thomasma has inspired all of the essays in this volume, which have attempted not only to reflect on the values and principles that have produced our contemporary practices and theories, but also to foreshadow the issues that David Thomasma contemplated and made his life’s devotion.

PART I

HEALTH CARE, HUMAN RIGHTS AND SOCIAL POLICY

DAVID C. THOMASMA

CHAPTER 1
EVOLVING BIOETHICS AND INTERNATIONAL HUMAN RIGHTS

INTRODUCTION

Ethics is evolving each year into a more and more international enterprise. Not only are the issues it concerns international in scope, but the new technologies challenge accepted cultural, religious, philosophical, and legal norms. This is especially true in the field of bioethics because the technological progress of medicine throughout the world is causing dramatic interactions with traditionally held values.

Too, our global knowledge of different cultures and the diversity of values increases almost daily (Cheng-tek Tai and Seng Lin 2001).[1] Science and technology are rapidly advancing beyond discussions and corresponding political struggles over human rights, leaving those debates behind. Examples abound, but good everyday examples might be the enhancement of human traits (Parens 1998), using informational technologies in health care or recent concerns about commercialization and commodification of human body tissues across national boundaries (Nelkin and Andrews 1998). These examples employ new techniques and appear to aim at human good yet raise concerns about limits and goals of health care, about privacy and about entrepreneurism in health care. Hence the rapid development of science and technology is at odds with the principle of sustained development that calls for measured and thoughtful planning, such that no new idea should rupture the delicate fabric of communities, environment, and cultural evolution (Callahan 1987).

Two challenges for human rights appear almost immediately. The first is related to how human rights might span different and sometimes distinct cultural and social boundaries. The second is the thorny problem of how to anchor human rights within the moral compass of individuals and societies.

TWO HUMAN RIGHTS DILEMMAS

One example of the first quandary comes from South Africa where at one time a dual system of health care provided care to whites and to blacks under *apartheid.* If a black came to the hospital emergency in a white system, the black was not to receive treatment there. In effect, such systems wherever they occur separate the question of human rights from ethics, personal and professional, creating enormous challenges for individuals who might object or try to circumvent the system (Purtillo 2000). The Truth and Reconciliation Commission's findings in South Africa have

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 11–24.

led to efforts to integrate teaching of ethics and human rights in medical schools (London and McCarthy 1998).

Other examples include the use of pregnancy monitoring technologies such as ultrasound to abort fetuses of the "wrong" sex in some countries (where a female's dowry can be a tremendous burden to the family), the sale of human organs in and between countries, possible harvesting of organs of condemned prisoners and their sale on the black market, research on prisoners, the commodification of human tissues, or the disjunction between the haves and the have-nots in many countries with respect to bone marrow transplants and other expensive medical interventions, while thousands of other children die for want of fundamental goods and services like clean water, basic inoculation, and food itself (Ocloo 1993).

Indeed, the earliest calls for a bioethics in the United States were made by Van Renselaer Potter who saw clearly that such a bioethics ought to be a global bioethics, that is, international in scope, with global and environmental concerns (1971). Recently Alastair Campbell recounted his experiences of lecturing in Brazil, and described how the situation there altered his conception of the very nature of bioethics.[2]

It must be acknowledged that in practice human rights are extended preferentially to certain classes of people, and that courts examine embedded legal rights but do not examine fundamental concerns like poverty and need. At the root of many critiques of the notion of universal human rights is the unquestioned right of private property. As a result, juridical human rights tend to coincide with the interests of elites since this right of private property tends to de-prioritize all other rights to work, food, adequate shelter, and affordable and accessible medical care (Engler 2000). As Juan Luis Segundo has remarked, "no court, national or international, will entertain a complaint of hunger" (1993, 61).

Thus, accompanying an increased global awareness and the acknowledged importance of different cultural values is a second problem about human rights, a questioning of the now-traditional basis for bioethical decisions. Can that basis, so culturally rooted and driven, be extrapolated to other countries? Can it be universalized? Specifically, can the principle of autonomy, which is so rich with meaning for Americans, be transferred to other countries as they grapple with ethical issues in clinical practice and research (Blackhall et al. 1995; Murthy et al. 1996)? Conversely, could the communitarianism of many European bioethicists find a home in the United States (Pellegrino 1992)? What of less individualistic conceptions of persons in Asian cultures, or even in Native American cultures (Kushner and Machay 1994)?

Martha Nussbaum has exhaustively examined this problem with respect to theories of justice and rights. All such modern theories depend in one way or another on the fiction of a social contract. Even Rawl's theory of justice has individuals meeting behind a veil of ignorance to decide how rights and goods are to be apportioned. Nussbaum argues that there is a common problem with all of these views – that of adult competence (2000). In fact, all of us enter life in a form of extreme dependency and, hopefully, within a family system of justice. The concretization of rights and duties are important in any schema that grounds bioethics in human rights.

Generally speaking, norms and principles in bioethics are thought to transcend specific cultural and ethical beliefs. Ruth Macklin proposes that the natural response to cultural pluralism should not be relativism, but an appeal to certain universals that transcend specific cultures and times (1999). In a pluralistic age, as Tristram Engelhardt once argued, it is philosophy that seeks to transcend culturally-driven values (1982). Yet, as we become more cognizant of various cultures and the values embedded in them, we see that norms are specified, as Patrick Norris argues, "within a context which integrates culture, religion, the law, professional standards, and organizational policies" (1996: 5). The current challenge for bioethics is to discover the appropriate integration of these contexts with more abstract norms that may transcend them.[3] Could bioethics worldwide be based upon some other principle like human rights (Veatch 1989)?

HUMAN RIGHTS

Before hailing human rights as the universal upon which to build an international bioethics, however, we should note that the human rights movement worldwide faces the same pluralistic quandary as does ethics. In the past, agencies such as Human Rights Watch were successful, on a case-by-case basis, in eliminating killings, disappearances, and torture in many countries, especially in the Western hemisphere. Each year, Amnesty International documents violations of human rights in both advanced and less advanced countries. For example, more than 100 governments used torture in their prisons or jails (including the United States), and 45 countries executed political prisoners or "troublemakers." In Amnesty's view there is an "appalling catastrophe of human rights violations" around the world (Anonymous 1993a). The basic rights violated were the right to dissent, the right to trial, and the right to repatriate (Anonymous 1993b). Human rights warnings appeal to culturally transcendent "rights" that were widely held and nonetheless individually violated.

Yet the challenges to rights-based ethics by Asian nations raise questions of cultural bigotry about such rights themselves. In 1993, for example, representatives of these nations questioned the very notion of human rights, put forth as international standards based upon the UN Charter, as imposing Western cultural norms on their societies (MacKinnon 1993). Specific to this problem is the observation made by Catharine MacKinnon, at the 1993 Amnesty International lecture at Oxford University that human rights as generally understood offer little protection to women (1993). Governments, impelled by specific cultural or religious values, can themselves be the source of evil when they turn the machinery of the state against their own citizens.[4] How then to appeal to universal standards that governments may acknowledge, for example in the UN Charter, but themselves violate in the name of some higher cause or even in the name of monetary competition?

There are few mechanisms available other than human rights to function as a global ethical foundation, a *Weltethik*, if you will. On the world stage, the argument for human rights as a general agreement of society begins with the Spanish conquest of the New World and the subsequent development of international law to protect the rights of natives as full persons.[5] The reason the notion of human rights can be so powerful is that it rests on a concept of the individual as having a human nature with embedded rights, metaphysically prior to any rights provided by cultural and political recognition.[6] This assumption, too, grounds the notion that norms and principles in ethics are also founded on more fundamental bases than cultures and politics. Not until the nineteenth century did the concept of a natural law come into profound question. Greater understanding of cultural variations and historicism led to this questioning, along with the discoveries of evolutionary biology.[7]

Post-structuralist thinking also suggests the relativity of human rights, not so much as they are grounded in different developing cultures, but instead from our responses to those cultures. The very concept of human rights is thought to marginalize the poor and the colonized in their miserable condition. How does this strange convolution occur? According to the French intellectual Alain Finkielkraut, the more we push ourselves to be enlightened and sensitive to multicultural perspectives, the more we end up acquiescing to the very things we oppose. In an effort to be just and fair, and thereby to avoid any taint of cultural imperialism, we seize on the principles of modern anthropology that often regard one culture as equivalent to another (Finkielkraut 1995).

Following this reasoning, we admit that the ideas of human rights and freedom we regard as so precious are really only cultural artifacts of one form of civilization, and should not be foisted on other cultures, at least not without their consent. Hence, at the end of the path of cultural pluralistic reasoning, we wind up acknowledging that human rights are fine for us in the West, but that oppression is acceptable for people in other cultures precisely because we must respect their own anthropological traits!

This irony occurs when the world community is faced with complaints that it imposes concepts of human rights on more communitarian societies that stress social altruism rather than individual rights. Moreover, within such (mainly Asian) societies, economic resurgence creates a double bind, such that economic opportunity is seen as the nemesis of the concept that controlled development should benefit all. The resultant individualism spawned by the new economy is considered by these countries to be an anathema.

Despite these cautions about appealing to human rights in bioethics, the modern, secular state based upon a constitution protecting human rights, provides obvious benefits in terms of individual freedom of expression.[8] Thus we rather happily no longer share the basic social common denominator of medieval society (and of fundamentalist movements), a common faith that is reinforced in all social structures. Instead, the moral voice is now one of persuasion with the force of international sanctions based upon human rights. If fundamental rights in bioethics are to be the moral basis of our actions in health care, then these must be proposed and adopted by international bodies like the UN and the World Health Organization. This important dialogue will require intense effort because intercultural communication is a most difficult and inadequate tool at present.

THE JUNCTURE OF BIOETHICS AND HUMAN RIGHTS

In the West, bioethics has often been grounded in rights-based thinking and language. More often than not, this thinking has centered on individual patient rights versus some system of power – medical paternalism, legal constraints on removal of therapy, or the dull machinery of hospital routine. Increasingly today there is a call to move beyond rights-based language in bioethics. Nonetheless, what is usually meant by this call is a turn towards the richer context of narrative or values within a patient or family context. Sometimes, of course, this involves cultural values, but again, in an orientation that is mostly singular and specific, rather than plural and universal. By linking bioethics and human rights the move from the singular to the plural is much broader.

Rights and Autonomy Perhaps the greatest challenge in this more universal perspective will be the search for a bioethics incorporating human rights that can be broader and richer than that yet to be accepted in all cultures, even traditional cultures that stress community over individuals. The preoccupation with autonomy and self-determination in Western bioethics, especially among American bioethicists, is indicative of the extent to which cultural values influence our orientation to biomedical morality.

Our beliefs about personhood and autonomy inform every aspect of medical transactions, including notions about consent and confidentiality in the patient-physician relationship. For example, in the United States and other Western nations, the individual is identified as the locus of decisional capacity for informed consent, even though in many of these countries indigenous populations use a communal or family model of decision making. The very concept of informed consent is almost meaningless in societies that stress the overriding importance of an individual's relationship with family and community. In these contexts, decisional capacity may only be socially expressed.

Similarly, the notion that one's privacy and confidentiality ought to be respected is thought to be a shared ideal in western cultures. However, this does not necessarily constitute a universal value. Social science research on beliefs and norms associated with the cultural construction of the self indicate significant variability concerning the relative importance of privacy (Gergen 1990). More empirical work is needed to improve our understanding of the moral nuances associated with personhood (Thomasma et al. 2001). Thus the primacy of autonomy is *not* a resolution for worldwide bioethics, but part of a more fundamental problem for most cultures.

Postmodern Relational Thought A world ethic must take into account the strengths and weaknesses of at least three major cultural responses to human relationships, as Archie Bahm argues (1995). The first is the Western emphasis on the will and reason, and the goodness of desiring, searching, and change. This is done under the assurance of pre-existing norms and standards that limit the excesses of such desire. The second response is found in Indian civilization, which stresses the dangers of willfulness and the evils of desiring and being different, indeed, the evils of any demarcation of the individual from the whole. The third is found in Chinese culture. It emphasizes the union of all opposites, the virtues of not going to extremes, of learning from one's family, and of participating in the lessons of practicality without becoming too abstract (Bahm 1995).

Perhaps the only way these contrasting cultures can be reconciled would be for a more relational conception of human being and consequent human rights to be developed (Tangwa 2000). This would require rethinking Western individualism, yet retaining the focus of the self within uniqueness and difference from others. In part, at least, people are the products of their own fictions. They are public narratives – stories constructed from their experience.[9] The greater the personage, the greater the hidden experiences that have not been portrayed in his/her own story. In a postmodern era, persons are not defined by their substance and individuality. In the thinking of Jacques Derrida, for example, the connections of persons are stressed over their individualities. This would be a fruitful avenue for development in bioethics as well.

In the West, change is always explained in the terms of what is, of Being, and measured against it. In different philosophies, what is, can be Being, substance, subject, person, mind, and the like. The effect of this thinking on bioethics is to distill one from one's circumstances, from one's actual life. Instead of privileging "presence" or identity or sameness, one emphasizes the importance of what is as "different" from other presences, from which emerges the much vaunted notion of personal autonomy.[10] Yet by arguing that difference is what is unique about individual entities, Derrida posits that the task of the individual is to articulate this difference. As this is done, one is inextricably tied to the context of the others by which one defines oneself. There is interplay here, a dialogue or narrative that is required within the very definition of one's being. Autonomy in bioethics thus cannot support individualism, but must intricate itself with others in the community.[11]

Common Language In bioethics discourse we often assume that conversation and dialogue can net positive results, particularly if, as Engelhardt argues, we all desire a "peaceable dialogue" (1992). The fact is that such conversation among people with opposite beliefs is extremely difficult. Erik Parens, describing a project of the Hastings Center that was to create consensus through multicultural dialogue in one institution in New York, notes:

> [We] found out how difficult it is for people who are significantly different to participate in mutually respectful conversation. Indeed, if one surveys the current shape of public intercourse across tables such as ours, across protest lines in Buffalo, or across disputed borders in the former Yugoslavia, it looks like human animals are hard-wired for suspicion and mistrust, if not fear and hatred; it looks like we are biologically constituted to detect and repel difference (1995, 197).

One of the most disputed questions in a world increasingly unified by communication is what direction multiculturalism should head. Because we are required by the modern world to critique our own cultural assumptions, should we retreat to the lost values of the past, embodied in our predominately White and Western society, African American or Native American roots, the Hinduism of India, Chinese social values, and so on (Ci 1999)? Or should we abandon those lost values for a new set of international rules that govern free social intercourse? After all, in the arts, it is not just the culture from which a work arises that is admired by others; it is the ability of that work to speak to something universal in the human experience.

Similarly, in ethical dialogue, if we stick to our cultural values and assumptions, and are unwilling to negotiate on some of the fundamentals, then we condemn multiculturalism in the best sense to a kind of multifractionalism. There is a common language that is rooted in cross-cultural and trans-historical values, but it takes *more* to ferret that language out in conversation. Often the discursive method of bioethics is faulted for being too lax on analysis. If we reach consensus, what do principles and rules or cultural values and even consequences matter? Exactly the opposite is true. Discourse and consensus are very hard and necessary work if we truly value a solid intercultural foundation for bioethics. A good example is provided by reproductive technologies.

Cloning, assisted reproduction, and embryo research are good examples of the exponential progress of science that challenges human rights. Guidelines are just now emerging about research on embryos. The Warnock Commission in England argued that embryos should have a "special status." The French and Canadian governments want to strictly limit such research. The United States would permit research under the "amber light" of caution (News and Comment 1994). However, a new class of beings, called "research embryos," will be created. These beings would be conceived in test tubes for the purpose of individuation (cell specification) advances to the point that they become separate, individual beings. Cross-species fertilization, creation of embryos solely for research material (for example, stem cells), and twinning and cloning will be ruled out for now.[12] Note, too, that the response worldwide to the cloning of sheep (Dolly and later, others) led to vigorous public denunciations of using this technology on human beings (Fitzgerald 1997). Although initial Canadian objections closely parallel the American position, Canadian legislators would forbid the sale of eggs and the maturation of fetal eggs for later implantation (Anonymous 1994).

What is interesting is that throughout the Canadian Commission Report an appeal is made to Canadian "ethical and social values" (Anonymous 1994). How are these determined? Can those values be extrapolated to all countries so that some set of international human values can be formed in bioethics? At what the point in the American research does the "amber light of caution" turn to red? Already a renegade scientist in Oak Park, Illinois announced his plan to clone a human being with funding from Swiss sources (Anonymous 1998). The standards have hardly been accepted and they are violated. Where to turn?

CROSS-CULTURAL BIOETHICS HUMAN RIGHTS PRINCIPLES

Thus far we have argued that bioethics needs to move beyond its established methodology to universals that appeal across cultures. Similarly health and human rights, in appealing to such universals, should not neglect the particularities of culture and traditions. Hard intellectual and political work can result in some cross-cultural principles based upon the Golden Rule, that is, based upon human efforts to determine how we would want to be treated by others ("Do unto others as you would have them do unto you"). Early in the Common Sense philosophical movement that took place during the Enlightenment, natural law was resurrected by appeal to the concept of an objective observer. This strategy can now be globalized. Recall earlier reference to the first conference on human rights in 25 years, sponsored by the UN in Vienna in 1993. Representatives of some countries argued that nations with a different, more communal tradition should be exempt from now standard international expectations about respecting human rights. The Chinese argued, for example, that human rights should be secondary to the needs of the state (such as law and order). This objection was rejected by the majority of countries (Anonymous 1993c). In fact, the conference ended with a proposal that the UN establish an office of high commissioner to protect and promote human rights around the world and a reaffirmation of the universality of human rights against a concerted effort to subordinate them to state or cultural considerations (Washington Post News Service 1993). The same conference recognized that "women's rights are an inalienable integral and indivisible part of universal human rights" (Washington Post News Service 1993).

Such widespread theoretical acceptance of fundamental human rights demonstrates that, to a large degree, our international expectations of individual rights help shape progress in developing our conceptions about how these rights are to be implemented.

Is there a basis in the structures of human existence for such rights (Marshall and Koenig 1996)? There can be, and a good example of a new and more sophisticated theory of natural law can be found in Erich Loewy's efforts to ground a universal ethics in the physiological capacity to suffer (1991). Loewy's argument is that by nature, all higher animals, including humans, can suffer. The basis of morality lies in this capacity and the obligation it imposes on us to respond to that suffering. Should this process prove too philosophically cumbersome, then bioethics based upon international human rights might still be carved out using contractarian theory, that is, a human rights ethic could be developed by persons accepting the duties they inscribe. We have proposed two types of rules – procedural (1 to 3) and substantive (4 to 7) – that could form the basis of international, multicultural bioethics (Thomasma 1997). They are summarized as follows:

1. The rule of peaceful dialogue

The virtue of multicultural discussion must be peaceful dialogue so that any underlying universal human experiences, such as suffering, incapacitation, illness, and death, can be explored in a mutual fashion. Only then can an inductive process occur that could form the basis of universal human rights in bioethics. We should agree with Engelhardt about the respect due to each individual in this process, but suspend any commitment to relativism as a solution to the problem (1986). The virtue of our times must be that of toleration, combining within it both a deep commitment to our own values and an appreciation, even celebration, of the values of others, which leads to the second rule.

2. The rule against xenophobia

As a matter of survival, cultures cannot remain closed to one another, nor can the relativism of cultural insights provoke a reaction so strong as to veer into cultural myopia or xenophobia. Myopia at least retains the illusion of being open to other insights; it is just that no one can be convinced of the merits of another viewpoint. As one commentator put it, "When you have different people with a different culture, you should expect clashes and arguments" (Cotliar 1995). Xenophobia, on the other hand, represents active disregard (even hatred) of other races or cultures.[13] Once again, it represents the stressing of differences to the point of forgetting how all people are rooted together in the world. In the words of Charles Taylor, "high ethical spiritual ideals are often interwoven with exclusions and relations of domination ... the great spiritual visions of human history have also been poisoned chalices, the causes of untold misery and even savagery" (1989: 518–9).

3. The rule of respect for cultural pluralism

It is important to recognize that culture is not a solid, impenetrable inheritance. Culture is more than a set of anthropological features. It is not like a genetic code that may determine behavior at all times. Rather, culture is the product of conversing, reading, writing, and commerce. It is something for which people in each nation strive (Englelhardt 1982). Culture can be defined as "the body of learned values, beliefs, and behaviors that characterize a group of people" (Perkins 1991: 72). In this way, culture provides a set of perspectives by which groups of people interpret their lives and what happens to them, including sickness and death. Bioethicists can be the beneficiaries of their richness of cultural perspectives if opportunities are created to experience the challenge of trans-cultural dialogue. And this challenge will require a new and perhaps uneasy acceptance (for some) of pluralism. As Patricia Marshall points out:

> One person's truth is another's conundrum... this perhaps is the key to understanding the subjective phenomenology and cultural diversity in questions of medical ethics. Whose judgment is correct? Where does the ownership of legitimacy reside? At the individual level, the answers to these questions are easier: the "right" morality is an expression of the heart as much as it is the head, and here we can all claim authority. But in matters of public policy, both nationally and internationally, the answers become distressingly clouded and ambiguous. Individuals may experience an abandonment of their particular "truth," and the struggle for ethical dominance and control over medical discourse and technology becomes voluble (1992: 62).

4. The rule of the common good

An alternative to autonomy as the basis of human rights and bioethical resolutions is the common good tradition that has influenced Western thought since Aristotle. In this tradition, individual good and rights coincide with the community's good. One cannot have one without the other. Rather than pitting autonomy against communitarianism, both are synthesized in a new common good methodology of bioethics analysis.

Communitarian ethics must rejuvenate bioethics discussion, which has become too complacent and reliant on standard analysis in terms of autonomy. The movement toward international debate regarding ethics and biomedicine must continue, even though consensus on issues may not always be feasible. More serious philosophical work, therefore, must be done on trans-cultural structures in human behavior and existence. However, several conditions for international, intercultural discourse about biomedical ethics are essential for effective development of the discipline.

5. The rule of cultural apprehension

Earlier, we pointed out the need for a kind of suspended animation about one's own cultural values when conducting intercultural bioethics. There must be simultaneous appreciation of another culture and suspension of total acceptance (that is, a suspension of total abandonment of one's own culture for the other). This is difficult, to say the least; we call this process *cultural apprehension*. If I abandon my culture and accept the insights of the other, for example, the Navaho Way of seeing the world (Freeman 1994; Carrese and Rhodes 1995), then my critique of my own culture supplants my culture with yet another way of thinking that may not be as good.

Yet, on what basis does one make intercultural judgments? Does the standard by which one judge what is good or better lie within one culture, or does it transcend all cultures? Does a person then become "acultural" in making comparative judgments? How is this possible? Would that person not be like the Flying Dutchman, a person condemned to wander the seas without an anchor in identity? Persons must be respected within the context of their culture.

6. The rule of respect for persons in context

The primary principle of international bioethics should not be autonomy or community, but dialectical respect for persons and enculturated values. The dialectical respect would be constructed similar to John Dewey's methodology of "reflective equilibrium," a method of balancing values without topping one with another *a priori* (Dewey 1938; Lowey 2000). Negotiation should not require that people abandon their cultural traditions and replace them with another culture's successes; rather, their cultural traditions should assist them and others to circumscribe an action or initiative with the values they profess. This means that we settle for tiny rather than giant steps.

7. The rule of existential a priori

As a consequence of mistrust, envy, cultural bigotry, and fear, discourse about biomedical ethics must have some *a priori* commitments. These can be called *experiential a priori*, because they may not be metaphysically defensible *per se.* These *a priori* arise from the past experiences of a culture whose history demonstrates the evil effects of ignoring such commitments. Among candidates for such *a priori* is the goal of assisting individuals to enhance their autonomy in the context of their family, to enhance their moral personhood in health care decisions. Another is the rights of all women to control their own reproductive gifts and not to be used as objects. These are two broadly developing international human rights that could inform medical ethics. Still other *a priori* might include those that emerge from collective experiences in reaching consensus about the actions of ethics committees or national policy committees (Bergsma and Thomasma 2000). Still others might be developed from experience, cultural history, and the nature of the healing relationship itself.

CONCLUSION

Both bioethics and human rights face relativistic challenges that are not insurmountable if attention is paid to those features of human existence and culture that unite human beings without overruling the very real differences. We have suggested in this essay a mean between too much emphasis on cultural differences that leads to relativism and a lack of international standards in bioethics, or too ready a smoothing over of differences in favor of universal standards or rights that would be seen as absolutes. The mean between these extremes requires appreciation and tolerance of the undeniable differences of cultures and the undeniable basis of individual human rights (Rorty 1989; Martinez 1996). An intercultural communitarian ethics must rejuvenate bioethics discussion because it has become too complacent and reliant on standard autonomy analysis. Yet such an ethic does not normally bear down on human rights so much as on the common good. Human rights are grounded in the community and in nature itself. They cannot be isolated from economic and social rights. This is what bioethicists will have to explore internationally and interculturally.

In fact, as the papers in this anthology demonstrate, that process has already begun. The movement toward international debate on ethics and biomedicine will continue to grow. Consensus on issues may not always be feasible, but several conditions we suggested for international, intercultural discourse about biomedical ethics are essential for effective development of the discipline.

NOTES

1. See, for example, an account of Catholic philosophers in the U.S. interacting with Continental philosophers and further developing their ideas in creative ways (Caputo 2000).
2. See his report in the IAB newsletter 2001.
3. What is needed in bioethics is comparable to what has been done about religious beliefs and human rights. See the authoritative distillation about protecting religious beliefs in Natan Lerner (2000).
4. A report of blows exchanged at a news conference at the 50th session of the United Nations Commission on Human Rights demonstrates just how difficult the process of developing a human rights basis for international and intercultural bioethics will be. A representative of the Sudanese Nation Islamic Front had just finished an extended interruption of a report on conditions in the Sudan, when he was attacked by a rival group member. In the words of a columnist, this "disorderly exchange at the usually somber commission lifted the thin veneer of decorum over the confrontations between victims and perpetrators...". The most heinous violations of human rights occur in the areas of the world we ignore most (Brown 1994: 19).
5. Early 16th century Spanish theologians Francesco de Vitoria and Dominic Suarez both proposed an international law based upon the laws and customs of countries (*jus gentium)* and on laws that transcend individual nations (*jus naturale*). These ideas were codified by Grotius at that time. Human rights spread more widely with the American Revolution, and most explicitly with the French Revolution's *Declaration of Individual and Civil Rights* (August 24, 1789). There was tremendous progress during the next two centuries, continuously extending human rights, even into international law.
6. Vittorio Possenti distinguishes two traditions in human rights, the secular and the religious, the latter deriving human rights from a law built into human nature by a Creator God (1995). Thus Thomas Aquinas, in the latter tradition, can derive human rights from inclinations of human nature – persistence in being, union between man and woman, generation and education of children, social character of human nature, and the desire for the truth. From these he argues for fundamental human rights respectively to life, to have a family, to procreate and educate one's children, to have a place in society and a useful job, and to develop one's own intelligence in a search for truth. Aquinas, T. *de lege*, in his *Summae Theologiae* 1,2ae, QQ 93–105.
7. Evolutionary biology is the notion that the specific nature of, for instance, a horse or a human being evolves and changes over eons.
8. Without secular protections, religious bigotry all too often results. Consider the Rushdie affair. Salman Rushdie wrote *The Satanic Verses*, which was highly critical of the Prophet Muhammad, and sexually offensive to Muslim leaders. Rushdie was condemned to death by Iran and the Ayatollah.

This led to international withdrawals of embassies by Western European countries. Internal debates about the freedom of the press and the freedom of expression occurred especially in England and the United States. Workers at mall-based book stores were threatened by calls and bomb scares. And the book was kept off the shelves. Full-page advertisements were taken out at Waldenbooks by Muslims defending their religion and their religious sensibilities. A similar occurrence involved the writings of Taslima Nasrin of Bangladesh, a physician and non-believer who is critical of Muslim views of women and marriage. She is now in hiding in Sweden. As she said of her own life, “They’ve taken everything from me...my innocence, my youth, now my freedom” (Weaver 1989: 60). Much of the Western reflection on the Rushdie and Nasrin affairs betrayed a note of cultural superiority. We admonished fundamentalist Muslims because they had not entered the golden era of responsible, international citizenship. Amnesty International took up the authors’ causes. Protests were lodged by Western governments with Iran and Bangladesh. Some countries threatened to cut off economic assistance. Yet, not that long ago, the power of Christianity was allied to the state for almost 1,000 years, during which time many persons were tortured and killed, put on racks and burned at the stake, for being different or refusing to follow Christianity. We escaped the “medieval and violent darkness” of Christianity, in the words of one commentator, “by depriving Christian religious authorities of political and legal power of the community” (Dyer 1989).

[9] See, for example ,how Anthony Powell developed this idea in his writings (Treglown 1995).

[10] That is, as Jacques Derrida argues, the opposite of “what is” is not “what is not,” but rather the difference itself. This approach keeps the individual rooted in circumstances, family, society, and culture (Derrida 1982).

[11] Derrida goes on to note that, by emphasizing difference, one deconstructs all efforts of establishing a kingdom. In his thinking, there can be no capital letters, not even I. No one perspective, for instance, autonomy, could govern our ethics. Rather the individual would be defined by his/her cultural context. In the post-modern view, even being as Is-ness is simply a choice. Being’s privileged place does not rest on some objective truth, but on a choice to emphasize being over non-being. Applying that to the Western emphasis on the individual, autonomy is not a side constraint of all ethics, but simply a choice to over-emphasize human difference to the exclusion of immanent ties to all things that are.

[12] Cross-species fertilization includes creating human beings using cow eggs and the like. Pigs and cows have already been created with human immunosystems. The creation of research embryos has not been ruled out in the United States, nor has human cloning, although these have been condemned by political leaders and other countries (Beck 1998; Neikirk 1998).

[13] A brief note about traditional Chinese xenophobia bears on this point. Chinese xenophobia is so entrenched that the story is told of the 200-year-old diplomatic failure of the British mission there. The British Crown sent Lord George McCartney to Peking in 1792 to exchange ambassadors and to improve how the Chinese were treating British merchants. McCartney was accompanied by huge warships and a retinue of 100. Yet the Emperor of the Ming dynasty treated the British as vassals, as he would Mongolians and Tibetans, and the gifts they brought as tribute. When McCartney arrived in Peking, according to Alain Peyrefitte, as a representative of King George III, he was herded together with many other subordinates to bring tribute for the Emperor’s birthday! The British simply did not understand the degree to which the Chinese regarded their empire as the center of the world (even though by then it had become quite poor and backward), or the degree to which the Chinese scorned business and businessmen (Peyrefitte 1993).

REFERENCES

Anonymous (1993a) Human rights took a beating in 1992: Group condemns 110 nations for torture, *Chicago Tribune* June 3: 2.

Anonymous (1993b) UN paper on rights criticized, *Chicago Tribune* June 3: 20.

Anonymous (1993c) Conference resolves dispute over rights, *Chicago Tribune* June 20: 14.

Anonymous (1994) Canadian Commission issues recommendations on new reproductive technologies, *Professional Ethics Report* 7: 7.

Anonymous (1998) Chicago physicist says he will try to clone humans, *Chicago Tribune* Jan. 7.

Beck, J. (1998) Cloning is not the path to immortality, *Chicago Tribune* Jan. 15: 23.

Bergsma, J. and Thomasma, D.C. (2000) *Autonomy and Clinical Medicine: Renewing the Health Professional Relation with the Patient,* Kluwer Academic Publishers, Dordrecht/Boston.

Blackhall, L., et al. (1995) Ethnicity and attitudes toward patient autonomy, *JAMA* 274: 844–5.

Bahm, A.J. (1995) What philosophy does the world need? *Contemporary Philosophy* 17:12–13.

Brown, B.A. (1994) Human-rights abuse is 'business as usual' in much of the world, *Chicago Tribune* April 15: 19.

Callahan, D. (1987) *Setting Limits: Medical Goals in an Aging Society*, Simon & Schuster, New York.

Caputo, J. (2000) Philosophy and prophetic postmodernism: towards a Catholic postmodernity, *American Catholic Philosophy Quarterly* 74: 549–68.

Carrese, J. and Rhodes, L. (1995) Western bioethics and the Navajo Reservation, *JAMA* 274: 826–9.

Cheng-tek Tai, M. and Lin, C.S. (2001) Developing a culturally relevant bioethics for Asian people, *Journal of Medical Ethics* 27: 51–4.

Ci, J. (1999) The Confucian relational concept of the person and its modern predicament, *Kennedy Institute of Ethics Journal* 9: 325–46.

Cotliar, S. (1995) Arab Americans cope with bias in suburbs, *Chicago Sun-Times* Feb. 6: 4.

Derrida, J. (1982) *The Margins of Philosophy*, tr. by A. Bass, University of Chicago Press, Chicago.

Dewey, J. (1938) *Logic, The Theory of Inquiry*, Holt, New York.

Dyer, G. (1989) The secularizing evolution that includes Islam, *Chicago Tribune* March 20: 13.

Engelhardt, H.T., Jr. (1982) Understanding faith traditions in the context of health care: Philosophy as a guide for the perplexed, in M.E. Marty & K.L. Vaux (eds.) *Health/Medicine and the Faith Traditions*, Fortress Press, Philadelphia, PA: 163–84.

_____. (1986) *The Foundations of Bioethics*, Oxford University Press, New York.

_____. (1992) *Bioethics and Secular Humanism*, Trinity Press International, Philadelphia.

Engler, M. (2000) Towards the 'rights of the poor' – Human rights in liberation theology, *Journal of Religious Ethics* 28: 339–65.

Finkielkraut, A. (1995) *The Defeat of the Mind* , tr. by J. Friedlander. Columbia University Press, New York.

Fitzgerald, K. (1997) Proposals for human cloning: A review and ethical evaluation, in J. Monagle & D.C. Thomasma (eds.), *Health Care Ethics: Critical Issues for the 21st Century*, Aspen Publishing, Gaithersburg, MD: 3–7.

Freeman, W.F. (1994) Making research consent forms informative and understandable: The experience of the Indian Health Service, *Cambridge Quarterly of Healthcare Ethics* 3: 510–21.

Gergen, K. (1990) Social understanding and conceptions of the self, in J.W. Stigler, R.A. Shroder & G. Herdt (eds.), *Cultural Psychology*, Cambridge University Press, Cambridge.

Kushner, T. and Mackay, C. (1994) Joseph J. Jacobs on alternative medicine and the National Institute of Health, *Cambridge Quarterly of Healthcare Ethics* 3: 442–8.

Loewy, E. (1991) *Suffering and the Beneficent Community: Beyond Libertarianis*, University of New York Press.

Lowey, R. (2000) *Integrity and Personhood: Looking at Patients from a Bio/Psycho/Social Perspective*, Kluwer Academic Publishers, Dordrecht/Boston.

London, L. and McCarthy, G. (1998) Teaching medical ethics: Teaching medical students on the ethical dimensions of human rights: meeting the challenge in South Africa, *Journal of Medical Ethics* 24: 257–62.

Mackinnon, C. (1993) Human rights watch looks within, *The New Yorker* 64: 53–4.

Macklin, R. (1999) *Against Relativism*, Oxford University Press, New York.

Marshall, P.A. (1992) Anthropology and bioethics, *Medical Anthropology Quarterly* 6: 62.

Marshall, P.A. and Koenig, B.A. (1996) Anthropology and bioethics: Perspectives on culture, medicine, and morality, in T. Johnson & C. Sargent (eds.), *Medical Anthropology: Contemporary Theory and Method*, 2nd ed. Praeger, Westport, CT.

Martinez, S. (1996) Indifference within indignation: Anthropology, human rights, and the Haitian Bracero, *American Anthropologist* 98: 17–25.

Murthy, S.T., et al. (1996) Ethnicity and advance care directives, *Journal of Law, Medicine & Ethics* 24: 108–17.

Neikirk, W. (1998) Senate opts not to vote on proposed cloning ban, *Chicago Tribune* Feb. 12: 4.

Nelkin, D. and Andrews, L. (1998) 'Homo Economicus': The commercialization of body tissue in the age of biotechnology, *Hastings Center Report* 28: 30–9.

News and Comment. (1994) Rules on embryo research due out, *Science* 265: 1024–6.

Norris, P.E. (1996) Culture and religion: Their role in ethics, *Health Care Ethics USA* 4, 5.

Nussbaum, M. (2000) The future of feminist liberalism, *Proceedings and Addresses of the American Philosophical Association* 74: 47–79.

Ocloo, E. (1993) Chronic undernutrition and the young, *Proceedings of the Nutrition Society* 52: 1–17.

Parens, E. (1995) The pluralist constellation, *Cambridge Quarterly of Healthcare Ethics* 4: 197.

_____. (1998) *Enhancing Human Traits: Ethical and Social Implications*, Georgetown University Press, Washington, DC.

Pellegrino, E.D. (1992) Intersetions of western biomedical ethics and world culture: Problematic and possibility, *Cambridge Quarterly of Healthcare Ethics* 1: 191–6.

Perkins, H.S. (1991) Cultural differences and ethical issues in the problem of autopsy requests, *Texas Medicine* 87: 72.

Peyrefitte, A. (1993) *The Collision of Two Civilizations*, Harvill, London.

Possenti, V. (1995) Human rights and human nature, *Contemporary Philosophy* 17: 4–10.

Potter, V.R. (1971) *Bioethics: Bridge to the Future*, Prentice-Hall, Englewood Cliffs, NJ.

Purtilo, R. (2000). Moral courage: Unsung resource for health professional as healer and friend, in D.C. Thomasma & J.L. Kissell (eds.), *The Health Care Professional as Friend and Healer*, Georgetown University Press, Washington, DC.

Rorty, R. (1989) *Contingency, Irony and Solidarity*, Cambridge University Press, Cambridge.

Segundo, J.L. (1993) Human rights, evangelization, and ideology, tr. by A.T. Hennelly, in *Signs of the Times: Theological Reflections*, Orbis Books, Maryknoll, NY.

Tangwa, G.B. (2000) The traditional African perspective of a person: Some implications for bioethics, *Hastings Center Report* 30: 39–43.

Taylor, C. (1989) *Sources of the Self: The Making of the Modern Identity*, Harvard University Press, Cambridge, MA.

Thomasma, D.C. (1997) Bioethics and international human rights, *Journal of Law, Medicine & Ethics* 25: 295–306.

Thomasma, D.C., Weisstub, D.N. and Hervé, C. (2001) *Personhood and Health Care*. Kluwer Academic Publishers, Dordrecth/Boston.

Treglown, J. (1995) Class act, *The New Yorker* Dec. 18: 108–11, esp. 110.

Veatch, R. (ed.) (1989) *Cross Cultural Perspectives in Medical Ethics,* Jones and Bartlett, Boston.

Washington Post News Service (1993) UN parley backs human rights office. *Sacramento Bee* June 26: A10.

Weaver, M.A. (1989) A fugitive from justice, *The New Yorker* 70: 60.

DAVID P. SULMASY

CHAPTER 2
DIGNITY, RIGHTS, HEALTH CARE, AND HUMAN FLOURISHING

Human rights and human dignity are intimately linked. Unfortunately, however, it is more common for both terms to be tossed about like slogans in bioethical debate than for either term to be seriously considered and examined. In this essay, dedicated to the memory of David Thomasma, I want to take a more careful look at the conceptual relationship between rights and dignity and how a clearer understanding of these concepts can contribute to a more robust discussion of the notion of rights in bioethics.

Dignity appears to be a more important concept in ethics than is sometimes noted. It is noted five times in the Universal Declaration of Human Rights of the United Nations.[1] The European Convention on Human Rights and Biomedicine also uses it five times, even including the phrase “Dignity of the Human Being” in the full title of the report.[2] Liberal rights theorists in the United States,, such as Ronald Dworkin, have noted the fundamental moral significance of dignity, yet decried its lack of clear meaning. Dworkin writes,

> Anyone who professes to take rights seriously, and who praises our Government for respecting them … must accept at a minimum, one or both of two important ideas. The first is the vague but powerful idea of human dignity. This idea, associated with Kant but defended by philosophers of different schools, supposes that there are ways of treating a man that are inconsistent with recognizing him as a full member of the human community, and holds that such treatment is profoundly unjust. The second is the more familiar idea of political equality.[3]

In other words, to speak clearly of human rights, one must have a clear conception of human dignity. The intimate relationship between these two concepts can be stated simply: People do not have dignity because they have rights; they have rights because they have dignity. In an ethical sense, then, dignity is prior to rights. We respect the rights of others because we first recognize their dignity. All human rights depend upon the concept of human dignity.

The idea of dignity, as Dworkin notes, is a fundamental Kantian contribution to ethics. Kant does not refer to rights. He refers to *Würde* (worth; dignity) as his fundamental moral concept. According to Kant,

> The respect I bear others or which another can claim from me, is the acknowledgment of the dignity of another man, i.e., a worth that has no price, no equivalent for which the object of value could be exchanged. Judging something to have no worth is contempt.[4]

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 25–36.

For Kant, once one understands what dignity means, one understands how one should act. First and foremost, *Würde* (dignity) commands *Achtung* (respect). It is respect for dignity that leads to the categorical imperative – that we should always treat people as ends-in-themselves, and never as means only.

RIGHTS: UNIVERSAL VS. LOCAL AND STIPULATIVE

The respect that we owe to those who bear dignity implies both what I will call universal human rights and local, stipulative rights.

Universal Human Rights. By universal human rights, I mean those that must always and everywhere be respected, binding individuals never to transgress them. Roughly, these will correspond to so-called "negative rights".[5] Generally, these will be what have otherwise been known as "natural rights" that apply to all people everywhere.

Local, Stipulative Rights. By local, stipulative rights I mean those that can be granted by various societies according to their particular means and particular conditions. Roughly, these will be so-called "positive rights" – rights to be given particular goods or services. Such rights can only be rights in societies that are capable of providing these services or substances universally.

The literature on rights is obviously vast and cannot be summarized adequately in a brief essay. Many aspects of rights theory are hotly contested. Without engaging the vast contested territory surrounding the thesis that rights and duties are correlative, let me then simply assert, for the purposes of this essay, that universal rights imply universal duties. Those rights I have called universal human rights correspond (roughly) to society's institutionalization of those other-regarding duties that Kant called duties of "perfect" obligation.[6]

By contrast, local, stipulative rights are derived from a subset of those other-regarding duties that Kant called duties of "imperfect" obligation. Some (but never all) duties of imperfect obligation can be socially institutionalized in particular times and places as stipulative rights. Factors such as wealth, geography, climate, culture, and level of technological sophistication of particular civilizations allow some societies, in recognition of the collective obligation of their members to pursue duties of imperfect obligation, to create local, stipulative rights that correspond to some of these duties. These duties, corresponding to such local, stipulative rights, become "perfectly" obligatory for those particular members of that society (some or all) who are charged with providing the goods or services until and unless conditions change and the society can no longer guarantee that the duty can be discharged in all cases. Under such circumstances, the "right" must revert to its fundamental status as the correlative of a duty of imperfect obligation.

TWO CONCEPTIONS OF DIGNITY

The word 'dignity' may be the basis for rights, but as Dworkin noted, it is not univocal. In its most general meaning, the word refers to worth or value. But there are at least two conceptions of dignity that are critically important in ethics and bioethics. One I have called *attributed dignity*, and the other *intrinsic dignity*.[7] These conceptions of human dignity are by no means mutually exclusive. Both are usually at play in the same situation, and, as I will show, one depends upon the other. Yet each has been taken as the basis for particular moral claims in bioethics, and different ethical norms result from taking one or the other as the central basis for those claims.

Attributed Dignity. By attributed dignity, I mean that worth or value that human beings confer upon others by acts of attribution. The act of conferring this worth or value may be accomplished individually or communally, but it always involves a choice. Attributed dignity is, in a sense, created. It constitutes a conventional form of value. Thus, we attribute worth or value to those we consider to be dignitaries, those we admire, those who carry themselves in a particular way, or those who possess certain talents, skills, or powers. We can even attribute worth or value to ourselves using this word. People use the word 'dignity' in this sense when they say it would severely diminish their dignity to be forced to wear diapers in order to avoid the even deeper embarrassment of incontinence.

Intrinsic Dignity. By intrinsic dignity, I mean that worth or value that people have simply because they are people, not by virtue of any social standing, ability to evoke admiration, or any particular set of talents, skills or powers. Intrinsic value is the value something has by virtue of being the kind of thing that it is. Intrinsic dignity is the value that human beings have by virtue of the fact that they are human beings. This value is thus not conferred or created by human choices, individual or collective, but is prior to human attribution, or, as Kant puts it, "humanity itself is a dignity".[8]

These two types of dignity evoke two relatively distinct sets of moral reactions in people. Attributed dignity evokes admiration, the loss of attributed dignity evokes compassion, and benevolence is the duty to build up the attributed dignity of others. By contrast, intrinsic dignity demands respect, and when someone is treated as if he or she did not have intrinsic dignity, justice, in its most fundamental meaning, demands a response.

Those upon whom we confer worth or value by attribution evoke our admiration. Logically, the attribution of worth or value suggests but does not imply admiration. One may recognize value in someone and still not admire him or her. One may, for instance, be jealous rather than admiring. Or, one may make a morally correct judgment that someone has a talent but is not worthy of admiration because of his or her misuse of that talent. So, one can say, "Goebbels was a master propagandist but still I do not admire him because of the evil use he made of his talent." But those whose level of attributed value is such that we attribute dignity to them command our admiration. Psychologically, to attribute dignity to someone and then to claim not to admire that individual would result in cognitive dissonance. We admire those to whom we attribute dignity.

Attributed dignity and the admiration it demands can have important moral value. We seek to emulate those we admire, and if we admire those persons for the right reasons, this can be very good.

But the true foundation for all moral duties is respect – that is – respect for intrinsic dignity. Certain acts are simply inconsistent with respect for intrinsic dignity. These are duties of perfect obligation and these other-regarding duties must be institutionalized by all societies. They correspond to universal human rights.

Respect really means more than acting in such a way so as never to violate universal human rights. Full respect also commands action in accordance with duties of imperfect obligation, even beyond those that particular societies have been able to institutionalize and codify as local, stipulative rights. Respect for intrinsic dignity is thus prior to attributed dignity. Respect for intrinsic dignity is the reason one is moved to compassion and benevolence in the face of assaults upon the attributed dignity of one's fellow human beings. Full respect for intrinsic dignity means not only that we ought never to transgress the rights that are derived from intrinsic dignity, but also means that we ought to take concrete steps to build up, imperfectly, limited by time, resources, and competing moral demands, the attributed dignity of our fellow human beings. In other words, as I will discuss in greater detail below, we have an imperfect obligation to help others to flourish.

NATURAL KINDS AND THE BASIS FOR INTRINSIC DIGNITY

Intrinsic value is the value something has by virtue of its being the kind of thing that it is. So, in a robust environmental ethics, non-human species have intrinsic value. This does not mean that they have an intrinsic value equivalent to that of a human being, but stars and whales and flowers have a value that we must recognize and do not merely confer. The recognition of this value makes moral demands upon us. We ought never, for instance, cause animals pain without some very, very serious reason.

It is membership in a natural kind that determines a thing's intrinsic value. This is what one means by the word 'intrinsic' – that the value of the thing in question is the value that it has by virtue of its being the kind of thing that it is.

The essence of a natural thing "is not some fancied vacuity parading in the shadow of familiar things" but rather, the precondition for the thing's being differentiated from the rest of reality as anything at all.[9] By 'natural kind' I mean the natural groupings by which the things of the universe present themselves in virtue of their sharing, even if imperfectly, particular properties and typical behaviors, but also some "'essential nature' which the thing shares with other members of the natural kind".[10] Ready examples include biological entities as lemons, or chemical substances such as uranium. A natural kind is not an artifact – not a class of objects created by human beings for human purposes. Nor is a natural kind a humanly invented designation of a class of naturally occurring entities that merely fits human instrumental or arbitrary purposes. As David Wiggins has stated,

> [The] determination of a natural kind stands or falls with the existence of law-like principles that will collect together the actual extension of the kind around an arbitrary good specimen of it; and these law-like principles will also determine the characteristic development and typical history of members of this extension.[11]

Lisska has called these law-like principles "dispositional properties".[12] These properties not only serve to describe typical members of the kind, they also describe the way typical members develop and behave and serve as standards for judging when a particular member of the kind is defective.

Intrinsic dignity is, so to speak, the intrinsic value proper to the highest order of natural kinds. Intrinsic dignity comes by way of membership in a natural kind that has, *as* a natural kind, the dispositional properties of intelligence, reason, love, free choice, moral agency, sociability, creativity, and other properties that constitute, at least in part, the basis for distinguishing this natural kind from other natural kinds and also the basis for intrinsic dignity – the value that an individual has by virtue of being *this* kind of thing. Importantly, I would argue that the individual members of *any* natural kind that has, as a kind, these dispositional properties, would have the value that I am calling intrinsic dignity. If, by supposition, there were such things as angels or Martians or other sorts of creatures that were to manifest, as natural kinds, these dispositional properties, then all the individual members of these natural kinds would have intrinsic dignity. But since this is an essay in philosophy, not theology or science fiction, I will confine my discussion to the intrinsic value of the human natural kind.

Intrinsic value is the value something has by virtue of being the kind of thing that it is. This value is not created or conferred by people but commands people's recognition and commands that people comport themselves in a manner consistent with the value that is recognized. This is especially true of the value we recognize as intrinsic human dignity.

The intrinsic value of human beings is the value I have called Intrinsic Dignity. It is the value that all people have simply because they are human. It is supremely democratic. It is inalienable. It does not admit of degrees. Respect for this value is the fundamental basis of universal rights.

"PERSONHOOD" AND DIGNITY

The competing basis for intrinsic human dignity and the rights that flow from its recognition is the concept of personhood. In this essay, I will use this concept in its contemporary, Anglo-American philosophical meaning. One should be aware, however, that for many centuries following Boethius, personhood and being a member of a natural kind capable of reason and moral agency were conceptually interchangeable. Boethius' definition of a person was "an individual substance of a rational nature".[13]

By contrast, contemporary Anglo-American philosophy divorces the concept of a person from being a member of the human natural kind. According to the contemporary view, 'person' refers to an individual member of a class or logical set, not an individual member of a natural kind or an individual member of kind that belongs to a particular class of natural kinds. On this conception, 'person' picks out only those individuals that actively express, as individuals, the particular characteristics that define the class, such as intelligence, reason, love, free choice, moral agency, sociability, creativity, and other properties. In other words, 'person' means not a kind of thing but an individual of which these properties can actually be predicated. Thus, some members of the human natural kind (e.g., embryos and the permanently comatose) are not persons, while some members of certain highly advanced non-human natural kinds (e.g., porpoises and higher apes) are (or at least may be) persons.

But this approach generates serious problems as a basis for dignity and a basis for bioethics. First, it would mean that there is no such thing as intrinsic human value –no value that a human being has by virtue of being the kind of thing that a human being is. This is a presupposition of the distinction between person and human being as it is set forth in contemporary Anglo-American philosophy. However, comatose human beings and cloned human embryos and Harvard professors are all the same kind of thing – human beings. All three are somewhat defective in their expression of the dispositional predicates of the human natural kind (some of those just listed are more defective than others), but all belong to the same natural kind. All three present themselves to us at different points in the characteristic pattern of development and typical history of members of this same natural kind. But not all of them fit the contemporary Anglo-American philosophical definition of a person. So, if by the word 'intrinsic' we mean a designation that arises by virtue of something being the kind of thing that it is, then 'person' cannot designate anything that has *intrinsic* value. The contemporary notion of a person does not designate a natural kind but a class that contains some (but not all) members of the human natural kind as well as some (but not all) members of other natural kinds. Therefore, the contemporary concept of a person can provide the basis for attributed dignity, but cannot provide a basis for a concept of intrinsic dignity. If one believes that there is such a thing as intrinsic dignity, it cannot be based on the contemporary Anglo-American philosophical definition of a person. 'Person' refers to a class, not a kind, and 'intrinsic' makes necessary reference to a kind.

One might object that even the designation that something has intrinsic value can only come about by human attribution, and so contend that the argument above is pointless. But this objection, of course, begs the question. It is no argument to say that there is no such thing as intrinsic value because all value is by attribution. The major premise already contains the conclusion.

All that I have proven is a conditional: *if* there is such a thing as intrinsic value, then the contemporary Anglo-American definition of a person cannot account for the intrinsic value of any human being. There is no absolute proof that there is such a thing as intrinsic value, but neither is there any absolute proof that all value is by human attribution. On the whole, though, the latter position seems implausible. It would appear to be profoundly egocentric, at worst, and deeply anthropocentric, at best, to suggest that nothing in the vast universe has any value whatsoever except in the minds of a few small specks of that universe crawling on the surface of the third planet from the Sun. That neither flowers nor porpoises nor galaxies have any value except in the minds of human beings raises profound questions about the pervasiveness of the skepticism being espoused – whether it encompasses skepticism about perception; if so, how there comes to be any shared perceptual knowledge; if not, by what basis this skepticism is to be limited to morals and not perception. While this essay cannot address these questions, suffice it to say that it would seem, at least, that the life of a chipmunk would have value for that chipmunk even if there were no human beings. And it seems equally plausible to suggest that other human beings have value for themselves without requiring that this value be conferred by other human beings. It simply makes more sense to say that things have value by virtue of being the kinds of things that they are than to say that things only have value in the minds of human beings.

Second, the dignity associated with personhood would, as attributive, necessarily be stipulative. This could be via an individual, idiosyncratic stipulation, or via a communal, inter-subjective stipulation. But since it would be stipulative in either case, it could not form the basis for any genuinely universal rights. As stipulative, the definition of a person could vary from place to place and time to time or even from one individual to another. And this would threaten to undermine the very concept of a universal human right. In a globalized era, the need for some statement of universal moral norms has become increasingly important. Universal human rights would seem to be the foundation of such a global ethic. On what other basis could one criticize national policies of forced sterilization or tolerance for female genital mutilation except by invoking universal rights? Yet the notion of universal human rights is possible only if it is based upon a truly universal criterion such as membership in the human natural kind. There is nothing else that human beings share commonly in so universal and radical a way as the simple fact that all are members of the same natural kind. It would not be possible to have such a truly universal notion of human dignity based upon a locally variable, stipulative account of personhood. One should recall that the United States Supreme Court's Dred Scott decision of 1857 stipulated that blacks were property and not persons at law. Attributions of value must be judged against some non-attributed standard if they are ever to be judged right or wrong.

This variability in time, place, and culture would be so no matter how what approach one used to stipulate the criteria for membership in the class of persons and thereby offer access to the protections afforded by its associated bundle of rights. Some, for instance, would suggest that membership in the class of persons requires meeting, as an individual, a threshold set of active capabilities – for example – sufficient rationality or a sufficient capacity for the expression of preferences. Others might suggest that membership in the class of persons depends upon the potential to develop or to restore these requisite capabilities. But since both the active expression approach and the potentiality approach would depend upon stipulations, both would be subject to rather arbitrary changes in exactly which actively expressed capabilities at what level of function (e.g., I.Q. of 35 or 40), or exactly which potentialities and at what level of probability (e.g., 1% vs. 0.1% chance of recovery from coma) would confer personhood, and therefore dignity, and therefore rights. Nor would there be any principled way for deciding that one or another threshold for membership in the class of persons were morally correct if personhood is itself the basis for being able to participate in deciding who is a person. This arbitrariness can hardly be the sort of stable moral bedrock one associates with the concepts of human dignity and human rights.

Third, if all values were only by attribution, and rights could only be conferred by membership in the class of persons, stipulatively defined, one would need to justify, morally, one's stipulation of the particular characteristics that define the class. But this exercise would quickly lead to an infinite regress of reasons. If all value were only by attribution, then the value one attributed to members of the class of persons could only be justified by giving good reasons for one's stipulative definition. But these reasons could only be good if one had some criterion for judging a reason to be good, and this would, in turn, need to be attributed to the process of giving good reasons. And if asked what constituted a good criterion for judging something to be a good reason, one would be forced, in turn, to attribute goodness to the criteria by which one judged something to be a good reason, *ad infinitum*. By contrast, the intrinsic value of membership in the human natural kind stops this infinite regress of reasons by positing something other than human attribution of value as a justification for morality – respect for the intrinsic value of others that commands respect prior to any human choice or attribution.

Finally, from the viewpoint of medical ethics, basing morality on the contemporary Anglo-American philosophical conception of personhood would fail to account for the moral meaning of much of medicine. Medicine implicitly depends on the concept of natural kinds. It is deviation from the biological dispositional properties of the human natural kind that constitutes illness. As Pellegrino has put it, medicine ministers to the "wounded humanity" of the patient.[14] But some of the wounds of illness actually eliminate one or more of the criteria listed in some stipulative definitions of personhood. Does one then say that one no longer has a moral obligation to treat such non-persons? Does one say that one no longer has a moral obligation to conduct research towards treatments for such non-persons? The natural kinds/intrinsic dignity approach, by contrast, would argue that the intrinsic dignity of the individual member of the human natural kind is never eliminated by disease, and that the obligation to treat, to attempt to restore the individual's wounded humanity, to conduct research with this aim, is based upon the individual's membership in the human natural kind, and not on the individual's "personhood". Of course, not all diseases remove one from the class of persons (e.g., *acne vulgaris* or the common cold). But the most serious ones (e.g., sudden cardiac death, brain cancer) do. And the recognition of a state as a disease depends not on how that state of affairs deviates from personhood but on how that state of affairs deviates from the characteristic development, typical history, biological dispositions, and flourishing of the individual as a member of the human natural kind – whether that disease is *acne vulgaris*, the common cold, sudden cardiac death, or brain cancer. The human experience of illness affects far more than the biological. It affects the whole human being. Good medicine attends to the effects of illness on the whole patient, including the patient's "personhood" as manifested in reason, freedom, love, moral agency, etc. But medicine begins with the biological, even if it does not end there. The natural kinds approach is inclusive enough to account for medicine as a human phenomenon. The "personhood" approach narrows the range of what counts as an illness and who counts as a patient.

NATURAL KINDS, HUMAN RIGHTS, AND HUMAN FLOURISHING

As David Thomasma, to whom this article is dedicated, once noted, "The reason the notion of human rights can be so powerful is that it rests on a concept of the individual as having a human nature with embedded rights, metaphysically prior to any rights provided by cultural and political recognition".[15] While the notion that anything, particularly a human being, has a "nature" has been unfashionable in philosophy for many years, the relatively recent philosophical notion of natural kinds, as explicated above, can supply all of the metaphysical substrate necessary for this concept of human rights.

I began by distinguishing two types of rights – universal human rights and local, stipulative rights. Before offering a fuller explanation of the philosophical foundations of these two types of rights, it will be necessary to introduce one final concept – that of human flourishing. Universal rights are rights because their violation is inconsistent with human flourishing. Local, stipulative rights are established on the basis of their capacity to promote actual human flourishing.

Flourishing is a state of affairs of a natural kind. For a plant to flourish means that it is able to achieve excellence in being the kind of thing that it is. This usually requires individual characteristics as well as a conducive environment – water, light, soil conditions, etc. Likewise, human flourishing means that human beings are able to become the best that they can become as human beings, and this also depends upon both individual characteristics and a conducive environment.

Human flourishing is both individual and communal. Because the human natural kind is inherently social and relational as a kind, human flourishing includes the social. The most vigorous conception of human flourishing is an integral, organic conception in which the common good in part constitutes the good of the individual.[16] On this integral conception, the common good is not merely the atomistic sum of the individual good of each, but the conception that the good of the commons and the good of others actually constitute part of my own good. To live in a town where the arts are flourishing is not just good for the artists and those who patronize the arts, but for Joe Jock as well, even if Joe prefers to watch baseball.

Perfectionist theories of ethics hold that the goal of morality is to promote human flourishing. The human good consists in the flowering of the dispositional properties that make us human, holistically integrated in all of our internal relations as individuals and socially integrated in the life we share with others as an inherently social natural kind.

Universal human rights, then, proscribe our acting in ways that would deny human beings their intrinsic dignity or prevent them from pursuing the values that they attribute to themselves or others, provided that the pursuit of these attributed values contributes to human flourishing in a fully integral sense. Local, stipulative rights, then, are those rights to goods and services that societies (to the extent that physical and social conditions allow) grant to individual members of those societies in order to foster conditions that are conducive to human flourishing in a fully integrated sense. Societies are obligated to grant such local, stipulative rights, as conditions allow, in order to promote human flourishing and are limited in their granting of any such right if it would detract from human flourishing.

IMPLICATIONS FOR MEDICINE

On this theory, certain rights relevant to healthcare are absolute – e.g. – the right not to be killed or tortured by physicians; the right not to be experimented upon without consent; the right not to be cloned. These are the universal human rights directed towards the direct respect for the intrinsic value of the human natural kind. These are negative rights. These are natural rights.

On this theory, however, the provision of health care would *not* be considered a universal human right, as I have defined this term. The provision of the goods and services of health care, which implies positive action, by definition, then, is not a negative right. Nor is it a natural right. The failure to provide health care does not, in itself, directly prevent persons from pursing the values they attribute to themselves or others. And under various conditions, certain societies simply will not have the resources to provide health care and therefore it cannot be universally required of all human beings.

However, the provision of health care ought to be considered an important local, stipulative right. A society that has the means to provide health care to its members has an obligation to establish access to health care as a local, stipulative right because health care contributes to human flourishing. Basic health care is an obvious contribution to human flourishing. It is an important and significant expression of human solidarity even under historical or social conditions in which it is not scientifically efficacious. However, in the 21st century, when medicine has become highly scientifically efficacious, health care can contribute to human flourishing in other highly important ways – by extending life; by relieving symptoms; by enabling creativity, love, productivity, and many other aspects of human flourishing. Health care does this by curing fatal diseases, ameliorating the limitations that illness can impose on human lives, relieving the burdens of symptoms, and soberly easing the pangs of finitude and death that are among the salient properties of the human as a natural kind.[17] Because the flourishing of the human natural kind is integrally social – i.e., the flourishing of the individual consists, in part, in the flourishing of the community – those who have the means to provide health care for themselves have an obligation to share their resources with those who do not. This is how one shows respect for the intrinsic dignity of each – the acts of compassion and benevolence that assist others in the pursuit of attributed values that contribute to fully integrate human flourishing.

This obligation to provide health care is limited, however, in several important ways. The first, as already discussed, is that the society must have the means to provide it in the first place. Second, the extent of the obligation is limited by the acknowledgement of a point of diminishing returns. Those societies (and individuals within societies) that have the means to provide for health care for others need not (and actually should not) give such quantities of their resources to health care that the human flourishing of each is diminished because the flourishing of the whole has been compromised by excess diversion of resources to the health care of the poor. Third, there is such a thing as too much health care. Excess attention to health care, even if it could be afforded and even if it were to improve marginally the physical health of a society, could diminish human flourishing by the cultivation of narcissistic attitudes or the fostering of a state of massive denial of the finitude that is among the defining features of the human as a natural kind.

CONCLUSION

In this brief essay, I have outlined a typology of human rights, distinguishing universal human rights from local stipulative rights. I have argued that the fundamental basis of all rights is intrinsic human dignity – the value that a human being has in virtue of being the kind of thing that a human being is. I have argued that the contemporary Anglo-American philosophical concept of personhood is an inadequate basis for intrinsic human dignity, and therefore an inadequate moral basis for the notion of universal human rights. Finally, I have argued that the perfectionist notion that the flourishing of humans as a natural kind is the goal of morality can be wedded to these concepts of rights and dignity to provide a robust view of human rights and human dignity. Universal human rights proscribe our acting in ways that would deny human beings their intrinsic dignity or prevent them from pursuing the values that they attribute to themselves or others, provided that the pursuit of these attributed values contributes to human flourishing in a fully integral sense. Local, stipulative rights are those rights to goods and services that societies (to the extent that physical and social conditions allow) grant to individual members of those societies in order to foster conditions that are conducive to human flourishing in a fully integrated sense. Societies are obligated to grant such local, stipulative rights, as conditions allow, in order to promote human flourishing and are limited in their granting of any such right if it would detract from human flourishing. On this theory, health care is not a universal human right but ought to be seen as a local stipulative right that each society has an obligation to provide to its members in a manner consistent with the human flourishing of that society.

NOTES

[1] "Universal Declaration of Human Rights" (http:// www.un.org/overview/rights.html)

[2] "Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine," ETS no.164 (http://conventions.coe.int/treaty/en/treaties/html/164.htm)

[3] Ronald Dworkin, *Taking Rights Seriously* (Cambridge, Massachusetts: Harvard University Press, 1977), pp. 198–19.

[4] Immanuel Kant, "The Metaphysics of Morals, Part II: The Metaphysical Principles of Virtue," Ak 419–420, In: *Ethical Philosophy*, trans. James W. Ellington (Indianapolis, IN: Hackett, 1983), pp. 80–81.

[5] The negative/ positive distinction is sometimes neither clear nor helpful, and this is one reason to seek a new classification such as the one I am proposing. See, e.g., Tom L. Beauchamp, *Philosophical Ethics* (New York: McGraw-Hill, 1982): 199–201.

[6] Immanuel Kant, *Groundwork for the Metaphysics of Morals,* Ak 421–422, trans. James W. Ellington (Indianapolis, Indiana: Hackett, 1981), pp. 30–32.

[7] See Daniel P. Sulmasy, O.F.M., "Death and Human Dignity," *Linacre Quarterly* 61 (November, 1994): 27–36; "Death With Dignity: What Does It Mean?" *Josephinum Journal of Theology* 4 (1997): 13–23; "Death, Dignity, and the Theory of Value," *Ethical Perspectives* 9 (2002): 103–118.

[8] Kant, "The Metaphysical Principles of Virtue," Ak 462, p. 127.

[9] David Wiggins, *Sameness and Substance* (Cambridge, MA: Harvard University Press, 1980), pp. 132–133.

[10] See Chris Daly, "Natural Kinds," In: *Routledge Encyclopedia of Philosophy*, vol. 6, Edward Craig, ed. (New York: Routledge, 1998), pp. 682–685. The quote is from Hilary Putnam, "Is Semantics Possible?" In: Schwartz SP, ed. *Naming, Necessity, and Natural Kinds* (Ithaca, New York: Cornell University Press, 1977), p. 104.

[11] Wiggins, p. 169.

[12] Anthony Lisska, *Aquinas's Theory of Natural Law: An Analytic Reconstruction.* (Oxford, U.K.: Clarendon Press, Oxford University Press, 1996), pp. 86–87.

[13] Boethius, "*Contra Eutychen et Nestorum*" ("A Treatise Against Eutyches and Nestorius"), III, In: *Boethius: The Theological Tractates*, transl. H.F. Stewart E.K. Rand, and S. J. Tester, (Cambridge, Massachusetts: Harvard University Press, 1973), pp. 84–85. This work is also sometimes called *De Duabus Naturis* and is famously cited in the *Summa Theologiae* of Thomas Aquinas, I, q. 29, a. 1, ad 1.

[14] Edmund D. Pellegrino, "The Humanistic Basis of Professional Ethics," In: *Humanism and the Physician.* (Knoxville, Tennessee: The University of Tennessee Press, 1979), pp. 117–129.

[15] David C. Thomasma, "Bioethics and International Human Rights," *Journal of Law, Medicine and Ethics* 25 (1997): 295–306.

[16] Daniel P. Sulmasy, O.F.M., “Four Basic Notions of the Common Good,” *St. John’s Law Review* 75 (2002): 303–310.

[17] Daniel P. Sulmasy, O.F.M., “Health Care Justice and Hospice Care,” Hastings Center Report 33 (March-April 2003): S14–S15.

REFERENCES

Beauchamp, T.L. (1982) Philosophical Ethics, McGraw-Hill, New York.

Boethius. (1973) Contra Eutychen et Nestorum, In: Boethius: The Theological Tractates, Stewart, H.F., Rand, E.K., and Tester, S.J. (transl.), Harvard University Press, Cambridge, MA.

Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. (1997) ETS no.164 (http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm)

Daly, C. (1998) Natural kinds, in Routledge Encyclopedia of Philosophy, vol. 6, Craig, E. (ed.), Routledge, New York.

Dworkin, R. (1977) Taking Rights Seriously, Harvard University Press, Cambridge, MA.

Kant, I. (1981) Groundwork for the Metaphysics of Morals, Ellington, J.W. (trans.), Hackett, Indianapolis, Indiana.

Kant, I. (1983) Ethical Philosophy, Ellington, J.W. (trans.), Hackett, Indianapolis, Indiana.

Lisska, A. (1996) Aquinas’s Theory of Natural Law: An Analytic Reconstruction, Oxford University Press, Oxford, UK.

Pellegrino, E.D. (1979) Humanism and the Physician, The University of Tennessee Press, Knoxville, TN.

Putnam, H. (1977) Is semantics possible? in Schwartz S.P. (ed.), Naming, Necessity, and Natural Kinds, Cornell University Press, Ithaca, NY.

Sulmasy, D.P. (1994) Death and human dignity, Linacre Quarterly 61 (November), 27–36.

Sulmasy D.P. (1997) Death with dignity: What does it mean? Josephinum Journal of Theology 4, 13–23.

Sulmasy, D.P. (2002) Death, dignity, and the theory of value, Ethical Perspectives 9, 103–118.

Sulmasy, D.P. (2002) Four basic notions of the common good, St. John’s Law Review 75, 303–310.

Sulmasy, D.P. (2003) Health care justice and hospice care, Hastings Center Report 33 (March-April), S14–S15.

Thomasma, D.C. (1997) Bioethics and international human rights, Journal of Law, Medicine and Ethics 25, 295–306.

Universal declaration of human rights (1948) (http://www.un.org/Overview/rights.html).

Wiggins, D. (1980) Sameness and Substance, Harvard University Press, Cambridge, MA.

GUILLERMO DÍAZ PINTOS

CHAPTER 3
HUMAN RIGHTS: THE ETHICS OF GLOBALIZATION

Human rights are rooted in the ideology proper to bourgeois liberalism. Considering the criticism that this recent ethical-legal tradition has received,[2] it is important to question whether human rights are universally valid or a bourgeois "ideological" trick (Ollero 1996, 378). That is, there are those who fear that "citizenship", or belonging to a political community, in relation to human rights, is used as a form of discrimination between individuals, which violates the inherent equality in the logic of rights and is the constitutive element in the ideal of justice. Human rights would then be the rights of the French, the Americans, etc., and therefore tied to a certain socio-political group or culture, which would obviously constitute a problem to their universality.

I will try to argue in favour of a position that maintains that the new social practice,[3] which begins in modernity with the presence of "natural rights," and evolves up to the current understanding of what are known as human rights, is the last expression of a universal ethics in which indispensable values that make communication and dialogue possible in a regime of moral pluralism are reflected.[4]

And this is so because in the *praxis* of human rights some anthropological assumptions are revealed, which turns them into a normative phenomenon in which the ethical condition of human existence, is reflected, in its search for an "ethical-juridical truth" that will rule social life. The assumptions implicit in the *praxis* of rights refer to:

1. The definition of justice, as the formulation of a social good or collective value, which rules and makes cooperation possible in a context of social and cultural pluralism.
2. The identity of the holder of human rights, as a subject that participates, actively or passively, in the definition and exercise of those rights.
3. Duty that, in terms of responsibility, requires the establishment of an order for human life, in a world in which technique has eliminated the inherent necessity of a "natural order," which previously provided the foundation for ethics.

HUMAN RIGHTS AND SOCIAL BOND

It does not seem daring to state that, in view of the origin and later development of human rights, the meeting point of all its internal variations and the basis of any attempt to provide theoretical coherence to their explanation, is the view which sees them as prerogatives or advantageous positions granted to individuals in order to protect their existence as a moral subject. The language of rights is therefore

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 37–44.

structured upon a moral foundation that places private conscience as its main axis, and is founded on man's self-comprehension as a being that is capable of projecting his own existence, which we usually refer to as an autonomous subject.[5]

The logic of rights is not necessarily identified with that which is part of the relationships between subjects, since not all individuals are capable of acting according to relatively unbiased criteria; while rights look at the protection of the moral life of individuals with equal respect and consideration. Consequently, rights are recognized in light of the validity of a subject's claims, and for this reason, the political recognition of individual autonomy, by protecting everything that contributes to form and express conscience's private judgment, demands an ethics of public discourse (Viola 1997, 297–298). This converts the problem of the conflict of rights into a central theme of political debate and demands that it develop on the basis of practical rationality and not on the principle of the dominion of power, albeit democratic power.

In this way, the dialogue on human rights, to the extent that it reflects an ethical demand, is the point of reference for analyzing the current moral convictions of an increasingly globalized society.[6] One can maintain that in the debate on human rights, upon bringing together the political recognition of individuals' autonomy with their interdependence, the doctrine of social contract, a product of liberal thought, is enriched. This is no longer interpreted as the union of men who are free and who freely accept associating with each other as a matter of convenience, but rather as the union of men and women who, in the same act of associating with each other, express and recognize their identity and freedom.[7]

This is so, as autonomy is achieved when one "wants" to have it, by responsibly facing oneself and one's own course of life, and making it have meaning in public discourse. Autonomy does not invalidate the reasons for preferring one life plan over another, since if it were merely choice that conferred value to a life plan, the difference between choices would be irrelevant and the only human right worthy of recognition would be the general right to freedom.[8] All other rights would be derivative of the organization of social life.

But the truth is that a person's autonomy is identified with the ends to which his choices are directed, and to deprive him of the possibility of attaining them is to violate his or her identity.[9] This is the reason that the list of rights continues to expand, protecting not only freedom of choice, but also choices already made within social contexts of co-operation. This requires a positive intervention by society, which gives rise to a particular concept of common good or collective well-being that may become detrimental to the independence of individual subjects. This is obvious with the growing importance of welfare rights.[10]

Consequently, the language of rights unfolds in a context of common meaning in which each individual is capable of giving "reasons" that can be understood and accepted by others. The widespread *praxis* of human rights assumes that every form of life in common carries with it a general idea of what is a life worthy of being lived, and that every person must be in a condition to judge himself or herself freely in regards to it.

In this way, the practice of the human rights, as a constitutive part of a social bond, turns into the language of politics and, as to the extent to which it is the expression of individuals' ethical demands, into the language of morality itself. It must be concluded that a moral subject's autonomy, which lies at the very core of the development of human rights, far from being a prerogative that separates persons, is the condition to participate in a common search in which personal and collective welfare are closely tied. This practice of rights is better explained from this perspective than from that of radical individualism (Gerwith 1996; Viola 1997, 351).

THE SUBJECT OF HUMAN RIGHTS

There is general agreement that the philosophical foundation of human rights requires a concept of a moral agent that is detached from his or her own particular conditions of existence and of the person as an abstract individual. This subject's capacity for free choice constitutes the foundation of respect that every human being deserves as such. It is believed that an impartial ethical theory requires this abstract model of the subject, considered as the basis for a rational process that leads to the determination of the principles that should govern social organization.[11] The person as a moral agent becomes in this way an empty and neutral referent, and his connection to his life's existential conditions, whichever these may be, are merely accidental, since they do not contribute in any way to conform the abstract identity of the subject considered in this manner.

This strategy consists first in establishing the moral principles upon which rights are based, on the basis of an individual who can conceive himself without them; and secondly in defining the types of individuals who possess the necessary qualities to enjoy these rights – to reach an independent and autonomous life – establishes a contingent relationship between the category of moral persons and that of human beings. According to this approach, the moral agent remains intact as a normative concept, while the category of beings that hold fundamental rights is a question of fact (Viola 1997, 363).

This goal of removing the moral subject from his existential conditions is acceptable in the measure that it hopes to avoid that respect for the person be founded in his or her own choices, rather than on a normative principle; but this creates a subject that rights cannot protect. According to this plan, the transfer of organs to the less fortunate could be considered just, applying Rawlsian "principle of difference", without it being considered that the person is being treated as a means (Rawls 1971). Thus, it appears that the more abstract the normative concept of a person is, the more discriminatory it becomes for real people.[12]

Upon assigning the value of autonomy to the moral agent considered above, it is appropriate to reject equating man or women, as individuals of the human species, with a moral agent. It is possible to think that the possession of certain qualities or of life under specific conditions, is what constitutes a person, and to exclude from this status other human beings incapable of self-reflection or communication, or those who find themselves in particular stages of life, or to include, for example, those animals which are capable of experiencing emotions (Singer 1985). This is not merely a theoretical question, since the concept of moral agent is commonly associated with a special dignity and consequently with the corresponding ethical-legal protection.

To deny equating man and person, due to the possession of certain qualities, or as a result of access to the different stages of life, assumes introducing an ontological discrimination at the heart of the human species itself, far worse than that of sex, race, or religion. It is clear that, if the existence of rights is tied to the condition of being a moral agent, and if society sets the requirements to reach that condition, the existence of human rights becomes dependent on a contingent decision.

It must be noted, however, that it cannot be determined which beings must be considered moral agents, and therefore worthy of protection, without laying a moral judgment of certain empirical characteristics (e.g., those who are capable of acting with conscience and freedom, or those who are capable of suffering, etc.). Therefore, it is also not justified to discriminate a purely normative concept of moral subject, within a larger category of beings empirically identified by their biological endowment, as would be the case with human beings. This is so because inevitably the idea of man is also a value-based concept, since it is inseparable from the understanding man has of himself. If, on the basis of current scientific knowledge, moral life is the common *praxis* that distinguishes the human species, moral and legal protection must completely fall upon it; this without there being any type of discrimination between the weak and the strong, the healthy and the sick, the most intelligent and those less capable, since all human beings, from the embryo to the terminally ill, participate as human beings in that form of life.[13]

A proper analysis of the *praxis* of human rights leads us to consider men and women without any subsequent limitations and in any of their vital expressions, as the holder of these rights and, as such, invested with a special dignity (Viola 1997, 363–364).

DUTY IN THE *PRAXIS* OF HUMAN RIGHTS

As previously stated, the practice of human rights shows us that the search for personal welfare is a venture closely tied to the creation of the common good in a context of dialogue, in which the value of one's decisions and life projects are not respected simply because they are "ours", but because they have an inherent value and are significant even for those who disapprove of them. In the creation of this common good, as will be outlined below, the moral category of duty and obligation is strongly manifested in the form of responsibility.

The freedom that human rights take into consideration, founded on the autonomy of the moral subject, is not man's control over nature as was implicit in the doctrine of natural rights. In it there was still a link between man and nature, in which man could control and govern it, because it was the basis of his existence, simply because of his biological need for self-preservation (Hobbes), or because of the unrenounceability of Natural Law (Locke). In any case, it was nature which provided moral objectives to man, while subjectivity was affirmed only at the level of means, as a "power" over it (Leyden 1987). Human rights assume, in their origin, a new understanding of freedom as ethical freedom, even from natural bonds. Choices come to depend entirely on subjectivity, and moral ends withdraw from their natural source. In this new *praxis*, the human being is his only arbitrator and must only account to his freedom But the evolution of human rights, with the enormous development of the so-called second and third generation rights, shows that freedom cannot be considered without reference to the communitarian context, or of the natural bonds characteristic of humans. If, in their origin, human rights were tied exclusively to freedom of choice, protecting what we freely wanted to be or do, more recently, it has been noticed that the individual also expresses himself through different common states and conditions that are independent of his or her free will: it is not in our power to control our age, or whether or not to succumb to illness, to be a man or a woman, etc. These states or situations bring people together, and thus individuals perceive that they could easily find themselves in the other's situation. Consequently, they are life conditions that belong to the human family; those who currently do not find themselves in those situations can still understand those needs, necessities and demands. In this way one can speak of a "communicability" of the existential situations of life (Viola 1997, 366–370). In the current development of human rights, one goes from safeguarding life's diverse individual situations to the protection of the different forms and states of life, hence the emergence of the rights of minors, women, elderly, patients, etc., that lack any value to the undifferentiated man typical of radical individualism.[14]

From an historical perspective, in this development of rights, the idea of "human nature" reappears as a guide towards an end that is found in every state of life, while at the same time freedom of choice is still recognized. Human rights are no longer manifest themselves, exclusively, as an instrument for achieving complete freedom from obligation, at which point man is free to construct his own identity, but rather in its *praxis* indicates the idea of duty that, under the form of responsibility, places us before a human value that must be cared for, respected, and looked after (González 1999). The moral subject is no longer evaluated only in relation to her independence, but also in the way she contributes to the impartial quest for the common good, since she is capable of perceiving others well-being just as they perceive it, and putting herself in their place. From this new perspective, the autonomous individual stops being the referent of isolation and of non-interference, as the principle of "harm to others" formulated by J.S. Mill suggests (1987, 68–69), to become that of communication and recognition of others (Viola 1997, 369).

Hans Jonas points out the reasons for the emergence of responsibility as a moral category that in our times gives shape to duty (Jonas 1994). It is not only about viewing a sense of duty from a responsibility point of view, but also in changing the way of understanding the latter as regards to its original meaning. As we have seen, reason has been the guide of collective action, the one that has restored with the prudence that corresponds to the definition of rights, the bond of man with his natural ends. It is also in this collective action where a new configuration of human responsibility can be perceived.

Today we find ourselves with individuals' responsibility for participating in cooperative actions, in which endless, relatively insignificant, single decisions can produce devastating effects in different kinds of complex systems; among which the ecological system is often mentioned. Faced with the enormity of this accusation, for an action in which one participates but whose effects cannot be controlled, individuals feel powerless to respond not in a frugal manner, or they escape from it, or pretend they are unaffected. This situation alters the traditional idea of responsibility, tied to the result of an action dominated in its causal link to the subject, and is transformed into a "co-responsibility" detached from a strictly individualistic dimension.

Co-responsibility cannot be understood as the mere sum of individual responsibilities; referring to the possibilities and threats derived from science and technology, such as the ecological crisis, genetic manipulation, or the concentration of economic power, we cannot separate ourselves from the idea of a collective action of global transcendence. This new perception of responsibility comes from individuals being considered members of a community of language and global co-operation in which, consequently, they see themselves engaged in an equally global system of responsibility. In this sense, co-responsibility summarizes individuals' openness towards the common good and to others needs (Viola 1997, 373).

These considerations reveal that the category of duty, adjusted to the development of human rights, has gone far from its original legal conception based on general and abstract rules and mechanisms of sanctions; it must correspond to the new dimension of responsibility, derived from a collective globalized action. This common action must address the goals already set forth by the very condition of man in the different stages of his life, and interests that are not strictly human or that belong to future generations (in fact they are here right now). For this reason, the moral and political language that lays the foundation for the *praxis* of human rights transcends the individualist dimension of the past, and its ethical meaning corresponds no less to the idea of autonomy than to that of solidarity and co-operation in the definition of the path for a genuine human freedom.[15]

CONCLUSION

The practical reasoning that guides the evolution of human rights reveals existing values and principles of justice that cannot become the object of bargaining or negotiation. To recognize them is the sign of belonging to a community of people and cultures that are co-responsible for organizing a dignified coexistence for man. Duty, from this perspective, finds a universal justification rooted in nature that has been entrusted to man for its custody.

NOTES

1. This contribution is due to an invitation by Prof. David C. Thomasma to make a reflection about human rights from an European perspective. I chose as a main inspiration the work of Prof. Francesco Viola, well known in Spain and in Italy: *De la naturaleza a los derechos. Los lugares de la ética contemporánea* (1997), from where it is quoted. The paper has been written in the context of the Research Project *Argumentación y negociación en los procedimientos democráticos de toma de decisiones* of the Universidad of Castilla-La Mancha, funded by the Ministry of Science and Technology of Spain.
2. The criticism of human rights do not follow any single assessment. Burke contemptuously called them "metaphysical rights" that hid their reality as rights of a people and culture. Marx described them as "rights to egotism," for having been claimed by the bourgeois class, ignorant of their social bonds and possessive of their belongings. Bentham saw behind them the spectrum of a nonexistent, supposed "human nature," considering them absurd from a logical standpoint and damaging from a moral one (Waldron 1987).
3. The genesis and evolution of this practice can be described, and therefore the life of rights is a fact that maintains its independence with respect to the variety of justifications that it has gone receiving throughout its recent history (Viola 1997, 300).

[4] Francesco d'Agostino (1993) affirms that human rights appear today with great evidence as the one true 'absolute ethics' of our time.

[5] The position taken by R. Dworkin is especially significant, for whom law incorporates principles that express convictions and practices characteristic of a sense of togetherness. These principles consist of propositions that compose rights and are developed by professionals and the general public over time. Rights, according to this author, are positions taken by the subjects that function as "trump" cards and overrule any other legal demand, political or ethical, that could come into conflict (Dworkin 1997, 89).

[6] A theory of law that does not admit any juridical reality prior to state laws would leave individuals defenseless facing their own demands. On this F. Laporta supports his affirmation of the placement of human rights in the sphere of ethics as moral rights, since it is not conceptually possible to simultaneously affirm that human rights are universal and that they are a product of positive legal order (Laporta 1987).

[7] Eloquently, Joseph Raz speaks of the classic liberal principle of "harm to others": "It can be derived from a morality that may consider personal autonomy an ingredient essential to the good life and may consider the principle of autonomy, which imposes obligations on people to ensure all of the conditions of autonomy, as one of the most important moral principles" (Raz 1986, 415).

[8] Liberalism recognises the freedom to choose a course of life but does not prohibit the reasons for choosing one over another. There are reasons for preferring one course of life to another, since not all concepts of good are equally legitimate (Viola 1997, 345–346).

[9] J. Griffin indicates that personhood concerns what is needed for human "status", but suggests that it is more generous to say that it concerns what is needed for human "flourishing" (Griffin 1986, 226).

[10] The growth of the importance of welfare rights shows that, in widening the possibilities of choice for individuals, not everyone's desires can be satisfied. This highlights the fact that one cannot be autonomous without the help of others. These are rights that require a particular intervention on the part of the State in order to be practiced (Golding 1984).

[11] J. Rawls proposes a concept of justice in which the principles that must rule social organization are the result of an original agreement where "free and rational persons concerned to further their own interests would accept in an initial position of equality as defining the fundamental terms of their association (…) In order to do this we are not to think of the original contract as one to enter a particular society or to set up a particular form of government (…) The choice which rational men would make in this hypothetical situation of equal liberty, assuming for the present that this choice problem has a solution, determines the principles of justice" (1971, 11–12).

[12] The origin of this line of thought is found in Descartes and was later adopted by Kant as the center of his system of thought. The identity of the Cartesian subject is immune to the experience of the man of flesh and bone, as he postulates a subjectivity exhaustively given as *res cogitans*. For Kant, the empirical "I" is a mere appendix to the transcendental moral subject (Díaz Pintos 2001, 634–635).

[13] In this way one can appreciate the usefulness of the expression human rights, given the confusion and existing controversy on the concept of person. To fully realize this, one only needs to observe the variety of theories on when a "human person" comes into existence: conception; implantation of the fertilized egg; when the fetus assumes a human form; when it is capable of living independently of the mother; when the nervous system is sufficiently developed; or not until the time of birth (Palazzani 2007).

[14] S. Cotta postulates a co-existential genesis of law, according to which subjective rights are derived from the ability to reach a common truth that may constitute the foundation of the obligation to obey the law. Rights are not recognized on the basis of unconditioned preferences of the individuals, but instead indicate the ontological limits that define both freedom and the will of the legislator. Consequently, this supposes the transformation of the respective goals of the subjects into the effort of establishing a normative order founded on a common truth (Cotta 1987, 45–50).

[15] Jacques Godbout defines the attitude that inspires donation, as that which inclines one to offer goods or services, without any guarantee of return, with the goal of creating, nurturing, or transforming the social bonds between people (Godbout 1998).

REFERENCES

Cotta, S. (1987) El derecho en la existencia humana, Eunsa, Pamplona.

D'Agostino, F. (1993) La giustizia tra moderno e postmoderno. Studi in onore de Vittorio Ottaviano, Giuffrè, Milán.

Díaz Pintos, G. (2001) The Medical Interpretation of Pain and the Concept of a Person, in Thomasma, D.C., Weisstub, D.C., & Hervé, C. (eds.), Personhood and Health Care, Kluwer Academic Publishers, Dordrecht/Boston/London.

Dworkin, R. (1997) Taking Rights Seriously, Duckworth, London.

Gerwith, A. (1996) The Community of Rights, The University of Chicago Press, Chicago.

Godbout, J. (1998) The World of the Gift, McGill-Queen's University Press, Montreal.

Golding, M.P. (1984) The Primacy of Welfare Rights, in Paul, E., Miller, F.D., & Paul, J. (eds.), Human Rights, Basil Blackwell, Oxford: pp. 119–36.

González, A.M. (1999) Naturaleza y dignidad. Un estudio desde Robert Spaemann, Eunsa, Pamplona.

Griffin, J. (1986) Well-Being: It's Meaning, measurement, and Moral Importance, Clarendon Press, Oxford.

Jonas, H. (1994) El Principio de responsabilidad. Ensayo de una ética para la civilización tecnológic, Circulo de Lectores, Barcelona.

Laporta, F. (1987) Sobre el concepto de derechos humanos, DOXA 4.

Leyden, W. Von. (1987) Hobbes and Locke, the Politics of Freedom and Obligation, Macmillan Press, Basingstroke.

Mill, J.S. (1987) On Liberty, Penguin Books, Harmondworth, Middlesex.

Ollero, A. (1996) Tiene razón el derecho? Entre método científico y voluntad política, Congreso de los Diputados, Madrid.

Palazzani, L. (2007) Person and Human Being in Bioethics and Biolaw, in Weisstub, D.N., & Díaz Pintos, G. (eds.), Antonomy and Human Rights in Health Care, Springer, Dordrecht, The Netherlands.

Rawls, J. (1971) A Theory of Justice, The Belknap Press of Harvard University, Cambridge, MA.

Raz, J. (1986) The Morality of Freedom, Clarendon Press, Oxford.

Singer, P. (ed.) (1985) In Defence of Animals, Blackwell, New York.

Viola, F. (1997) De la naturaleza a los derechos. Los lugares de la ética contemporánea, Comares, Granada.

Waldron, J. (1987) Nonsense Upon Stilts: Bentham, Burke, and Marx on the Rights of Man, Methuen, London.

AMNON GOLDWORTH

CHAPTER 4
HUMAN RIGHTS AND THE RIGHT TO HEALTH CARE

INTRODUCTION

I speak of human rights rather than moral rights because what I am referring to is distinctly human, whereas moral rights, at least for some people, are possessed by animals. In addition, being treated fairly, or as an end not solely as a means, or having promises kept, are moral rights, but they are not distinctly human rights according to my proposed thesis.

My analysis will concern itself only with those human rights that are attributable to the born. The purported rights of the unborn, which have been espoused in contemporary discussions, will not figure in this essay because the issue of their existence is so in dispute that we are unable to settle the question whether the unborn have any rights, or if they do, whether these constitute human rights.

My main objectives in this essay are twofold. First, I will offer an original account of human rights that attempts to answer the question, “What does it mean to say that a person has a human right?” This account will be based on a social contract perspective and will make specific reference to the notion of adequate compensation. It will disavow any appeal to God or to a God-centered natural law, and it will not rely upon some special view of human nature. My second objective is to determine that there is a human right to health care as based upon my general conception of human rights.

Once this first objective has been achieved, I will identify the specific human rights that emerge. Some, such as the right to life, freedom or liberty, have traditionally been recognized. However, the purported right to property, espoused by John Locke and included in the *Virginia Bill of Rights*, the French *Declaration of the Rights of Man* and the United Nations *Universal Declaration of Human Rights*, is an extremely restricted human right. The right to health care, which is included in the United Nations Declaration and the right to die which is not, as far as I know, included in any list, are human rights according to my analysis.

I begin with an historical survey of natural rights, or human rights as they are called today. I conclude this survey by conceiving of human rights as a claim against the world which is based upon some basic human need or interest. This is not an original view. What is novel is my use of the notion of adequate compensation as a necessary condition for the existence of a human right. This notion emerged from Jean Jacques Rousseau’s discussion of slavery in Book I, Chapter III of his *Social Contract*. But, it is not at all clear that Rousseau recognized the existence of human rights or natural rights as he would be wont to call them. In any case, the notion of

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 45–54.

adequate compensation as related to human rights was not exploited by Rousseau nor by anyone else until now.

In Sophocles's play, Antigone is driven to disobey the command of Creon, not to bury her slain brother in order for her to obey a higher law. These are her words to Creon:

> Nor did I think your orders were so strong that you, a mortal man, could over-run the gods' unwritten and unfailing laws. Not now, nor yesterday, they always live, and no one knows their origin in time (1954, 450).

Although the notion of natural rights, which today is commonly referred to as human rights, did not come into being until several centuries had passed, Sophocles' words speak to that concept in contrast to the notion of rights derived from positive law. What are some of the rights that have been identified in the past as natural or human rights?

John Locke, in his *Two Treatises on Government*, asserted that human beings have a natural right to life, liberty, and property.[1] This is also claimed in the *Virginia Bill of Rights of 1776.* In the same year, the American *Declaration of Independence* stated that human beings have a self-evident and inalienable right to life, liberty, and the pursuit of happiness. In 1789, The French *Declaration of the Rights of Man* asserted the right to life, property, security, and resistance to oppression. And in 1948, The UN *Universal Declaration of Human Rights* enumerated the following rights: life, liberty, property, equality, justice, social security, adequate living standards, medical care, rest, and leisure. John Locke derived his list of rights from right reason. But, right reason appears to be a poor guide given the variety of rights suggested above.

What is unusual about the UN Declaration is its inclusion of economic and social rights. Traditionally, such rights have been politically rather than economically or socially based. The reason for this is that the former entail negative duties to desist from interfering with human conduct rather than positive duties to bring about certain results. The former are obviously more easily achieved than the latter. But, once a certain level of well-being is reached, people come to recognize the possibility of claiming rights to certain economic or social states of affairs. One such emerging claim is the right to health care.

SOME FACTS IN THE HISTORY OF HUMAN RIGHTS

In some Hellenic city-states, notably Athens, citizens had rights, such as equality before the law and freedom of speech. After the city-state ceased to be a viable political entity, due to the military actions of Philip and Alexander, followed by the growing dominance of Rome, people could no longer treat such rights as civil rights because civil society, as it had previously existed, disappeared. Stoic philosophers reformulated the pre-existing civil rights as universal rights. They held that these did not derive from civil law but from a higher law which reason could discover. As Cicero observed, "True law is right reason in agreement with nature; it is of universal application, unchanging and everlasting" (1928, Bk. III, XXII, 211). This "true law" was called natural law.

Natural law and natural rights were important concepts in the Roman world in the Middle Ages in which they were thought to be derived from God, and in the 17th and 18th centuries, in which they played key roles in justifying human freedom and in supporting revolutionary causes. But, in the 19th century, these concepts were dismissed. Consider the following remarks of the radical philosopher, Jeremy Bentham, and the political conservative, Edmund Burke. According to Bentham:

> Rights is the child of law; from real law comes real rights; but from imaginary laws, from 'law of nature,' come imaginary rights ... Natural rights is simple nonsense; natural and imprescriptible rights ... rhetorical nonsense, nonsense upon stilts.[2]

Edmund Burke objected to talk of natural law because he felt it misled people into thinking that they possessed something that they did not and thus aroused them to revolutionary action which destroyed traditional institutions and practices (1968, 124). Burke was quite right about the effect of talking about natural rights, but was wrong in dismissing them.

Scorn of natural rights doctrine continued into the 20th century. The emergence of German and Italian fascism resulted in widespread criticism. These attacks could not be based upon the fascist laws that were being criticized. Instead, people turned to the independent criterion of natural law.

The following is a contemporary description of natural rights as presented in *The Dictionary of Philosophy*:

> By "natural rights" we understand the subjective rights that man possesses as a human being, which are granted to his person for the protection of certain essential interests. These rights are considered the irreducible ... patrimony of every human being as part of his very nature ... As a consequence, these rights are inalienable and imprescriptible. Inalienable, because if these rights would be given up, man would cease to be a person and become a case of alienation; imprescriptible, because if these rights ceased to exist ... man would likewise cease to be a person in his prescribed condition.

An important addendum to this description of natural or human rights is that although these rights do not cease to exist, one right can trump another when there is a conflict between the two. This will be explained below.

If we compare positive legal rights and human rights, we see that the former are rights that people do actually possess; the latter are rights that people are entitled to but do not necessarily possess. This will also be explained below.

SOME TRADITIONAL VIEWS

Before turning to my position, I want to cast doubt on a number of traditional views: first, that natural or human rights are dependent on natural propensities or on human nature; second, that natural or human rights are derived from God; third, that rights derive from Kant's categorical imperative; fourth, that rights derive from general utility.

There are natural propensities that do not serve as the basis of human rights; for example, our propensity to play games. Thus, to know which propensities are connected to human rights, we already have to know what human rights are. There are also features of human nature that do not serve as the basis of human rights. It is not important to know specifically what these features are because, whatever they are, we need to ask why we are being selective. And doesn't our being selective indicate that rather than our human nature determining what our human rights are, we are asserting these rights and then selecting certain features of human nature that conveniently support them?

It has also been said that natural or human rights are God-created. This I believe is a mistake. In Plato's *The Euthyphro*, Euthyphro declares that piety is what is pleasing to God. In response, Socrates asked Euthyphro whether what is pious is so because God is pleased with it or whether God is pleased with it because it is pious (7–10). It is generally understood that God, being who He is, would only be pleased by what is pious. But, this is to make the concept of piety definable independent of God's pleasure.

To say that natural or human rights derive from God is no more significant than making the blanket statement that God created everything. It becomes significant only when it is supported by efforts to demonstrate that God does define natural or human rights. But such attempts are bound to fail not on the platonic grounds found in *The Euthyphro*, which are dependent on syntactical features of classic Greek, but for reasons having to do with the way we think of God in relationship to these rights. First, God approves of what is right because if He were to do otherwise, He would not be God. Second, if God was said to approve of something that we believed was morally wrong, we would deny that He was the source of this approval. The first of these considerations indicates that what we view as morally right is guaranteed to meet with God's approval. The second makes it impossible for there to be any assertion of what is morally right which we do not accept. Both of these rule out the possibility that God determines what is right.

But what if one believes that it is within God's power to make anything right?. This is theoretically possible. However, these God-made rights must exist, to borrow Immanuel Kant's discourse, in a nominal world that can never be known in our phenomenal world, given our moral intuitions. Thus, God stands on the sidelines so far as our knowledge of human rights is concerned.

Kant's categorical imperative says that human beings, as persons, are to be treated as ends and not merely as means toward satisfying the ends of others. This provides for a defence against certain forms of abuse or exploitation, such as slavery or the involuntary use of human beings in medical experimentation. But it is questionable whether the categorical imperative or the Kantian concept of personhood can establish such generally acknowledged human rights as the right to life or the right to personhood.

In his book, *Utilitarianism*, John Stuart Mill said, "To have a right ... is... to have something which society ought to defend me in the possession of. If the objector goes on to ask why it ought? I can give him no other reason than general utility" (1948, 40). But if one can give no other reason than general utility, then given its contingent nature, it could admit something to be right that is wrong. For instance, servitude, whether legal or *de facto*, such as slavery or economic bondage, is right if, as has happened in the past, it maximizes utility. Or, of more immediate importance, general utility might make it right to neglect the serious medical needs of a few in order to satisfy the less serious needs of many.

THE NATURE OF HUMAN RIGHTS

To assert a moral right is no guarantee that one will have it satisfied. One may make the claim and fail to have it recognized. This can occur for two reasons. First, the claim may be arbitrarily refused even though it is morally justified. This is what happened to slaves who demanded their freedom. Second, one may justifiably refuse to accept the claim because either it is not morally justified or because the objective conditions by which the claim can be realized do not exist. The latter is what presently limits the serious application of the economic and social human rights claims enunciated in the UN *Universal Declaration*.

MY CONCEPTION

What sort of human rights can legitimately be claimed? Living in society involves a compromise between the advantage of social existence and the disadvantage of constraints on one's behavior. The advantage of social existence derives from the strength of numbers and the security that a collective provides, and the fact that social cooperation makes possible the use of many hands where two hands do not suffice. But, social existence requires us to inhibit those self-regarding interests that are antisocial in nature. We are willing to forgo the satisfying of such interests because we receive adequate compensation for the absence of their accompanying satisfactions. But we cannot forgo certain interests because no adequate compensations are possible. This is the case no matter what sorts of institutions or practices define a given society. Our interests in life and liberty – with certain qualifications, as we shall see – are of this sort. Thus, what is the most important feature of a human right is that *a failure to satisfy it deprives a person of a benefit for which there is no adequate compensation*. Since there is no genuine alternative for human beings to social existence, leaving aside the rare loner, the failure to satisfy an interest should always be viewed in a social context.

What I have just said is suggested by Jean Jacques Rousseau:

> To renounce one's freedom is to renounce one's status as a man, the rights of humanity and even its duties. There is no possible compensation for anyone who renounces everything. Such renunciation is incompatible with the nature of man, and taking away his freedom of will is taking all morality from his actions (1978, 50).

Rousseau did not develop this argument much beyond what he said above. I will now offer some qualifications to my thesis, as suggested by Rousseau, and then identify and discuss the nature of specific human rights in the light of this account.

First, by speaking of a person being deprived, I mean to restrict the range of human rights to human needs and interests that are vital or fundamental to all. Someone might have an intense need for a particular Stradivarius violin for which there could be no adequate compensation, if lost or stolen. But, such a need is idiosyncratic and therefore not admissible.

Secondly, the phrase "not being able to fully compensate someone for the loss of human right" is intended to mean that what this right gives to people is irreplaceable.

Thirdly, human rights are absolute in the sense that they are possessed by all human beings, past, present, and future. Thus, the concept of human rights is not time dependent or community dependent. What is both time and community dependent is the way in which human rights are exercised. However, they are not absolute in the sense of being incapable of being overridden or in the sense of being incapable of being restricted in their application.

Fourthly, human rights can be promoted by civil society either directly by law or by social convention, or indirectly by maintaining institutions suited to the exercise of these rights. But, they are not rights that can be conferred by civil society since they are already possessed.

Fifthly, human rights can apply to either external or constitutive objects. The total deprivation of food, which is an external object, cannot be adequately compensated. But, some deprivation can be. Being deprived of one's brain, which is a constitutive object, cannot be adequately compensated. But a pint of blood can be. External and constitutive objects will be discussed further as part of the analysis of property as a human right.

Sixthly, because of the potential for interpersonal conflict, civil existence places constraints upon human rights. These constraints define the space within which one person is free to exercise his or her rights and others are allowed to enter only with permission. Thus, while it is appropriate, in the abstract, to refer to the human right to x, it is more precise to say, "the human right to x, in a social setting, is the right to x for A, consistent with the same right for B, C, D...N." Why is it more precise? First, if the human right to x means the right to all in the Hobbesian sense of not entailing any corresponding obligations, then the only persons capable of having human rights are psychotics and babies. Second, if the human right to x for A does entail a corresponding obligation on the rest of the community, B, C, D...N, then in some circumstances the satisfying of that right for A will deprive the same right for B, C, D...N. But, this violates the absolute condition for human rights.

Seventhly, there are several conditions under which a person can make a claim to a human right when he or she is not permitted to do so by social circumstance. First, when he or she is not allowed to exercise a human right as others in the community are. This constitutes what may be called a communal inconsistency. Second, when he or she is not allowed to exercise a human right as others in other communities can. This constitutes what may be called a comparative inconsistency. This, unlike the first is problematic since what is realizable in another community may not be in one's own. Third, when he or she is not allowed to exercise a human right as he or she conceives it possible to do in some, as yet, non-existent but possible community. This constitutes what may be called conceptual inconsistency and, given the need for conditions of realization, is highly problematic.

Eighthly, my compensation-based conception of human rights implies that if I am adequately compensated for the loss of some benefit, then this benefit does not constitute a human right. For example, if I choose to die in order to save the life of another or to forgo a particular liberty in order to act in a principled manner, we can assume that I have been adequately compensated for my sacrifice. Appearances to the contrary, this does not constitute an exception to my theory. We applaud or feel great sympathy for such sacrifices because they are laudable actions. But, notice that they are not motivated by needs or interests that are vital or fundamental for all. Thus, they do not meet the first qualification mentioned above. If they did, I would be led to say that there are human rights to such sacrifices that trump the rights to life or liberty. But, if we put this aside, how are we to characterize such sacrificial acts in the context of my compensation-based conception?

Choosing not to speak does not imply that I have given up my right to speak. Choosing to sacrifice a particular liberty, like the liberty to speak, does not imply that I have given up my human right to liberty. Thus, the human rights to life or liberty are not violated if one, in an act of sacrifice, chooses not to exercise them. But, there is indeed one circumstance in which the explicit violation of a human right is justified, namely, when we punish an individual for the commission of an antisocial act.

PUNISHMENT

Inflicting punishment by depriving an individual of his or her liberty or life violates that individual's human rights. In what way can this social practice be understood and justified given this violation? The first thing to observe is that this question is interesting only if we assume the existence of a society in which individuals are satisfied with the arrangement of benefits and burdens and in which human rights are respected. No one will voluntarily agree to a permanent social arrangement in which he or she has an unsatisfactory share of burdens or in which his or her human rights are capable of being violated with impunity. An individual may agree to an unfair social arrangement out of necessity. But being coerced or having no choice are clear indications of involuntary behavior.

Retributivists tell us that certain actions are inherently bad and that the perpetrators deserve to be punished or that punishment is designed to purge the criminal of his or her guilt or that punishment redresses the moral balance for the community. Consequentialists justify punishment in terms of its effectiveness as a deterrent to future criminal acts. Neither the Retributivist nor the Consequentialist provides us with a helpful way of dealing with the apparent incongruence between punishment and human rights. Let me approach this problem from another perspective.

I observed earlier that social existence is a compromise between freedom and security. We forgo some of the former in order to gain some of the latter. Social stability depends upon the degree to which individuals are satisfied with the arrangement of benefits and burdens. A part of that stability is created by the assurance that can be provided to achieve and maintain security. Otherwise the trade-off between freedom and security would be at risk. Any criminal act violates an established social arrangement of benefits and burdens. The criminal renounces the burden of non-interference by doing injury which others have voluntarily forgone. Thus, the criminal gains a benefit that has not been agreed upon by others and generates a burden for others that may also include violations of their human rights. Punishment of the criminal is the only means of social protection available to those who have voluntarily limited their own freedom. In order to be effective, punishment must include the violation of the human rights of the criminal. One cannot adequately compensate such an individual for a violation of his or her own human rights. But punishment is the only deterrent to the violation of the rights, human or legal, of others.

APPLICATIONS

The plausibility of a scientific account is dependent upon its power to explain and predict empirical phenomena by the application of its general principles. The plausibility of a political account, such as I am proposing, is dependent upon its ability to blend facts and values in a way that is intuitively appealing. Let me then turn to the following set of issues to see how my theory concerning human rights plays itself out in specific applications and contexts: the right of life, the right to die, the right to freedom or liberty, the right not to be tortured, the human right to property, the exercise of human rights and punishment, and finally, the right to health care.

The Right to Life. The right to life heads the list of human rights. It is treated as such by all claimants and in all theories. In my theory, it is established as a human right by the fact that there is no method of adequately compensating a human being for the loss of his or her life when life has positive meaning. Efforts to compensate someone – usually a family member – for a life lost is society's way of trying to do the best it can to rectify a wrong. But this is no substitute for this loss of life.

The Right to Die. The dying process has become a matter of serious concern in contemporary life. Before the Second World War, doctors provided comfort and care, but nature generally determined the outcome of illness and disease. Since that War, medicine has increasingly pre-empted nature. One of the results of modern medical technology is the lengthening of life with a subsequent increase in chronic disease. Another result is the ability to prolong the dying process. Both of these innovations have produced pain, suffering, and alienation from others.

I asserted above that there is a human right to life when life has positive meaning. But, it may not have such meaning. Instead, it may be filled with unrelenting pain or suffering that prevents a person from attending to any other experience, or an incapacity for human interaction. In such circumstances, the right to die trumps the right to life since there is no way of adequately compensating a person by maintaining his or her life. Formally stated, a person has the right to die when a failure to permit a person to die, either by withdrawal of aid or by hastening death, results in that person being deprived of a fundamental need not to experience inextinguishable pain or suffering or alienation. Put less formally, we have a human right to die when living itself is so deeply deprived that it has no redeeming quality.

The Right to Liberty. The right to liberty or freedom is either of a political or non-political nature. The former claims we have a right to be free from external interferences which threaten losses to us for which there is no adequate compensation. The latter concerns those serious hindrances to our freedom which threaten the realization of our human potential.

Certain liberties or freedoms, either political or non-political, can be trumped by the right to life. This is exemplified in the social contract in which some liberty is voluntarily sacrificed in order to achieve the security of one's person.

The Right not to be Tortured. In discussing torture, Eric Stover and Elena O. Nightingale observed that,

> Torture is the deliberate infliction of pain by one person on another in an attempt to break down the will of the victim ... Nothing negates one's sense of what it means to be

> human more than the deliberate infliction of unnecessary pain and humiliation on a helpless victim (1985, 4).

Nothing can adequately compensate a person for the loss of his or her humanity. Thus, the use of torture constitutes a violation of a human right.

The Human Right to Property. Property and the right to it has been a major social concern ever since, as observed by Rousseau, someone bethought himself to enclose a piece of land and to call it his own. Interest in property and property rights have served as the basis of our understanding of rights in general. However, our interest is in determining whether the right to property is a human right.

John Locke would have us believe that reason tells us that it is, and that humankind possesses it prior to existence in civil society.[3] Rousseau claims that the right to property is a conventional rights and not a human right because every person can dispose of what he or she possesses at will. No such divestiture is possible with the rights to life and freedom (1964, 164). Thomas Jefferson held that it was debatable whether any sort of property is a human right (Dumbauld 1955, 56). Who is correct, Locke or Rousseau and Jefferson?

Property refers to something we own and which we can use and dispose of. It is usually, but not necessarily, material in nature since we can possess intellectual property. It is usually, but not necessarily, fungible since we can dispose of property as a gift or exchange it for honour or position. Some, but not all the parts or portions of our bodies are exchangeable property. A person can use and dispose of some blood but not all and continue to remain a person. There is no way that a person can be adequately compensated for the loss of those parts of the body that places the person at serious or certain risk of the loss of his or her life. But adequate compensation is possible for the loss of disposable body parts, material objects that we own and intellectual property. We may, as Rousseau put it, have a conventional right to property, but the only property rights that are human rights refer to things we cannot do without and continue to survive.

The Right to Health Care. The human right to health care is clearly linked to the rights to life and non-political freedom. Health care is either life-preserving or serves to alleviate or eliminate sickness or suffering which are barriers to our ability to develop fully as human beings.

Why is the claim to the right to health care a recent arrival, given that such care has been available for thousands of years? In past centuries, those who had sufficient funds could secure the services of physicians, and those who did not used folk medicine, were supported by charitable agencies or simply allowed nature to take its course. But people during these centuries did not speak of a right to health care. It was not until the middle of this century that there was a general recognition in advanced industrialized countries that the material conditions needed to satisfy the right to health care were present. This was followed by the emergence of national health plans and entitlement programs.

But, in response, someone might argue that there are medical interventions that do not deal with the vital needs of the patient and therefore are not covered by the human right to health care. This argument fails to take account of the fact that the biological and psychological integrity of a person depends upon adequate organic activities which are closely dependent upon one another. We can survive the loss of one kidney or a portion of the liver. But we may not survive the failure to attend to those conditions that can lead to kidney failure or liver disease. Thus, all organic insufficiencies can be viewed as affecting the vital needs of the individual.

Given that the right to health care is a positive right that generates obligations on the part of others, rather than being a negative right that obliges individuals only to refrain from doing harm, against whom is the claim to health care to be made? As suggested above, where material conditions are obtained that make the wide application of medical care possible, such as the presence of a large number of health care practitioners supported by an array of education, managerial, research, and pharmaceutical facilities whose existence is financially secure, then the claim to health care becomes significant. This claim can then be made against those individuals involved in the health care network according to the roles that they play.

CONCLUSION

In the early part of this essay, I quoted Antigone as saying that there are higher laws and that "no one knows their origin in time." I have made an effort to determine their origin and by so doing, to identify human rights and warrant their existence.

NOTES

1. Locke, J. The Second Treatise of Civil Government, Ch. II, no. 6.
2. Bentham, J. Political Fallacies, Art. II, 32.
3. Locke, J. The Second Treatise of Civil Government, Ch. V, no.s 26 and 27.

REFERENCES

Burke, E. (1968) Reflections on the Revolution in France, Penguin Books, Ltd., England.

Cicero (1928) De Re Publica, Bk. III, XXII, 211, Putnam's Sons, New York.

Dumbauld, E. (ed.) (1955) The Political Writings of Thomas Jefferson, Bobbs-Merrill, Indianapolis.

Mill, J.P. (1948) Utilitarianism, The Liberal Arts Press, New York.

Rousseau, J.J. (1964) The First and Second Discourses, St. Martin's Press, New York.

_____. (1978) On the Social Contract, St. Martin's Press, New York.

Sophocles (1954) Antigone, in D. Grene and R. Lattimore (eds.), Sophocles 1, The University of Chicago Press, Chicago.

Stover, E. and Nightingale, E.O. (eds.) (1985) The Breaking of Bodies and Minds: Torture, Psychiatric Abuse, and the Health Profession, Freeman & Co., New York.

DAVID E. GUINN

CHAPTER 5

RELIGION, INTERNATIONAL HUMAN RIGHTS AND WOMEN'S HEALTH: SYNTHESIZING PRINCIPLES AND POLITICS

For many people at the turn of the millennium, human rights have become the new language of faith as it resonates with great meaning and profound value. However, like all traditional religions, human rights embody great complexity (Ignatieff 2001). Neither coherent nor consistent, human rights cannot overcome the fallibility of its human creators. When we attempt to use rights as absolute values – Dworkin's (1984) trump cards against infringement – we find ourselves confronting the contradictions inherent in equally valued rights when they come in conflict.

As noted by many authors, nowhere is this conflict more pronounced than the conflict between women's rights and the rights of freedom of conscience/religion present in many international human rights instruments (Mayer 2000–2001). Lest this be thought a problem of Western privilege, where women can afford the luxury of seeking political parity with men, in this paper I will confront human rights conflicts that have a direct impact on women's health. This will include both reproductive health concerns and female circumcision/female genital mutilation.

In attempting to address these conflicts, I will begin by analyzing the nature of human rights to health and the particular rights of women to health – with the problems created by their separation from non-gendered rights. Next, I will begin my principled argument by arguing against both an absolutist understanding of rights, and a "strict equality" standard of interpretation that seeks to recognize a hierarchy of rights. Such an approach fails as a matter of law, as a matter of philosophy (under the foundationalist challenge), and in the face of history. Instead, I argue that while a principled interpretation of rights can provide some guidance, its utility is limited. Instead, it is imperative to consider rights within their political context. Human rights do not stand outside politics, but instead reflect aspects of that politics. Ultimately, the goal of any rights analysis is not to determine which rights take precedence, but how to find a synthesis respectful of each.

HEALTH AS A HUMAN RIGHT

Defining health as a human right, and determining what that means, presents some conceptual challenges. The public and scholarly discussion of health and human rights is of relatively recent origin. As late as 1994 it could still be said that, "Health and human rights have rarely been linked in an explicit manner. With few exceptions, notably involving access to health care, discussions about health have not included human rights considerations" (Mann et al. 1994). Nonetheless, the idea

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 55–72.

that health is a fundamental human right was present at the modern birth of the human rights movement following the Second World War.

While the first iteration of human rights as an international standard of law, set forth in 1945 in the United Nations Charter, was little more than an assertion of a commitment to promote and encourage “respect for human rights and for fundamental freedoms,” the meaning of the term human rights was quickly fleshed out (United Nations 1945). By 1946, the United Nations had shepherded into creation the World Health Organization. The WHO, within its Constitution (World Health Organization 1946), defined what is meant by the term health as “… a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO 1946).

By 1948, the United Nations General Assembly adopted the Universal Declaration of Human Rights, an exposition on the nature and content of the term human rights that was subsequently developed into the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (United Nations General Assembly 1948 (hereinafter UDHR); United Nations General Assembly 1966; United Nations General Assembly 1966). Collectively, the three are known as the International Bill of Human Rights.

Without the insights provided by the WHO definition of health, one might be misled to the conclusion that the human rights related to health, as articulated in the UDHR, were rather shallow, embracing simply a “right to life” (Art. 3) a “right not to be tortured” (with the health consequences associated with that) (Art. 5) and the right “to a standard of living adequate for the health…of himself [sic] and of his family, including food, clothing, housing and medical care” (Art. 25(1)) In terms of health, the ICCPR and the ICESCR essentially “implemented” these norms with certain elaborations, such as the ICESCR’s requirement that the States Parties “recognized the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” and that the states take steps to address problems such as infant mortality, environmental pollution, treatment of epidemics, and the availability of medical care(Art. 12). However, in light of the WHO definition, the rights articulated in the International Bill of Rights must be understood as health related human rights whenever they affect “physical, mental [or] social well-being.” The definition therefore embraces the related rights though separate disciplines of medicine (focused on individual health) and public health (Mann et al. 1994). Thus, the legal import of this broad definition is that states not only have a duty to prevent or remove barriers to the realization and maintenance of physical, mental and social well-being, they also have an obligation to promote health, social, and related services, along with cultural reform to remedy potential social harms (Cook 1994).

Given this extremely expansive understanding of health, virtually every human right embodies an element of health. Thus, the WHO may reasonably assert that the human rights obligation of states to promote and protect health embodies a demand not simply to attend to the provision of “physical and mental health services, but to the justice of the foundations upon which societies function” (Cook 1994). In assessing “health human rights” no limits apply. Not only do the instruments of the International Bill of Rights afford grounding, virtually every succeeding human rights instrument adds to the realm of health human rights. Whether it involves protection against genocide, war crimes, or racial discrimination, all have clearly recognizable effects on health and human well-being (UDHR 1948; ICCPR 1949; ICESCR 1965). Moreover, the United Nations and the international system were quickly supplemented by regional treaties and organizations in Europe, America and elsewhere, that echoed and sometimes advanced the ideas set forth in their international counterparts (European Convention 2003; Inter-American Convention of the Prevention, Punishment and Eradication of Violence Against Women 1994).

While the WHO definition of health justifies this broad understanding of health related human rights, the definition risks to become meaningless. If health is synonymous with human rights, health adds nothing to the conversation. Thus, it is useful to identify human rights to health as those rights whose derogation or promotion results in measurable effects in physical and/or mental health, either at the individual or social level. While making the concept of health related human rights more manageable, this limitation still allows for a very wide range of health rights. For example, the impairment of economic rights (such as unionization, rights to property, or a decent wage) could clearly create a socio-economic status detrimental to a person's physical and mental health (UDHR 1948; Adler et al. 1999). The health consequence of an impairment of these rights merely becomes one point of entry through which to consider the rights violation, or provides grounds for a legal or political compromise in the face of a conflict of rights.

While health related human rights were clearly intended to be included within the catalogue of international human rights, the nature, extent and character of these health related human rights remains subject to debate. While those health rights arising under the ICCPR, the Genocide and other related conventions that protect the health of individuals from harmful state action (particularly actions that would directly threaten their right to life, or physical integrity or dignity) are strongly protected, those health rights that may impose an affirmative duty upon the state to provide economic or social resources have traditionally been much more limited (ICCPR 1966; UN 1973; UN 1984). For example, while the ICCPR mandates that member states have an affirmative, immediate obligation to protect all of the rights identified in the ICCPR (except for a limited number of political rights that may be derogated in times of public emergency), the ICESCR merely obligates State Parties to "undertake steps…to the maximum of its available resources…to achiev[e] progressively the full realization of rights recognized in the [ICESCR]" (ICCPR 1966; ICESCR 1966). Thus, in evaluating any human health rights claim, it is important to determine the source and nature of the state obligation.

WOMEN'S HEALTH AND HUMAN RIGHTS

In theory, once it is established that a human right to health exists within the foundational human rights documents the United Nations Charter and the International Bill of Human Rights, the sole remaining questions should be as to the nature and extent of those rights. Gender, for example, should be irrelevant. After all, under the United Nations Charter, a principle aim of the UN is to "promot[e] and encourag[e] respect for human rights and for fundamental freedoms for all without distinction as to…sex" (UN 1945). In each of these documents it is specifically affirmed that human rights accrue to "all members of the human family" by virtue of their status as human beings (UDHR 1948). They are entitled to the protection of those rights "without distinction of any kind… [including by virtue of] sex" (UDHR 1948). Both the ICESCR and the ICCPR share a common article 3 requiring State Parties to "ensure the equal right of men and women to the enjoyment of all" of the rights provided in those covenants (cite).

Unfortunately, history is replete with examples of states failing to protect the health rights of women. They fail in two ways. First, they fail to protect the equal rights of women compared to men. For example, women in some countries are often denied access to health care without the permission of their husbands or a male relative or where the health care provider is a male (Cook and Maine 1987; Iacopino et al. 1998; Physicians for Human Rights 1999; U.S. Department of State Bureau of Democracy, Human Rights, and Labor 1999). More extreme are violations to the health right to life denied by acts of violence directed against women, such as the practice of honour killing (Mayer 2000–2001, 259–260). Less direct abuses of health rights arise from economic and social practices of discrimination. For example, HIV transmission to women is enhanced through the economic dependence upon men and upon the fear of violence that precludes their demanding that their partners use condoms – even when they know that partner to be infected with the virus (du Guerney and Sjoberg 1999). Similarly, the common practice of treating home care (both familial domestic labor and child care) as non-economic labor denies women occupational benefits available to most workers; similarly, the tendency to compensate positions traditionally held by women (e.g., nursing, teaching, domestic workers) less then comparable jobs traditionally held by men may result in denial of access to health care and/or a lower standard of living with adverse health consequences (Cook 1994).

The second way in which states fail to protect women's health rights occurs when they fail to address the unique health needs of women. Reproductive health rights represent the most obvious of these sexually specific health concerns. For example, 500,000 women die from maternity-related causes every year; lifetime risk varies by region ranging from 1 in 16 in Africa, 1 in 65 in Asia and 1 in 1,400 in Europe (UN 2004). On an even more fundamental level, states fail to protect women when, in their regulations of medicines and medical research, they omit requirements to conduct medical trials sensitive to the biological and potential therapeutic differences between men and women (American Medical Association Council on Ethical and Judicial Affairs 1991).

In response to this failure to protect women's health rights, and more broadly, women's human rights, advocates began to urge the recognition of a category of women's rights (Cook 1994). This, in turn, led the UN and other international bodies to sponsor and/or promulgate a significant number of declarations, programmes of action, and conventions addressing the human rights of women (Alfredsson and Tomasevski 1995). Among the most important of these is the Convention for the Elimination of Discrimination Against Women (CEDAW 1979). In terms of health rights, CEDAW specifically protects women from discrimination in the field of health care both to assure equal access to health care and access to gender specific services relating to maternity (CEDAW 1979). More generally, drawing on the

WHO definition of health, it protects women from social and economic discrimination that would affect their right to work and the consequences of their frequent vocation in the "non-monetized sectors of the economy" (CEDAW 1979).

The movement to protect women's rights was clearly intended to enhance the protection of women's rights, but has in fact resulted in a diminution in protection (Howland 1997, 349). This movement does not stand alone in suffering this type of unintended consequence. The unfortunate tendency in international law to promulgate a large number of specific instruments often results in increasing confusion and ambiguity rather than enhanced rights (Bassiouni 2003). Singling out special groups for protection after the promulgation of general right raises the suggestion that the original document was not intended to protect that group. Repeatedly identifying limited, specific rights suggests that unnamed rights may be exempted (CEDAW 1979). Finally, and most damaging to women's rights under CEDAW, segregation of women's rights from men's rights has allowed sexual politics to intervene and introduce limitations on women's rights that would not have been allowed if men were the subject of the limitation. For example, while the Apartheid Convention (which clearly includes men) expressly rejects any cultural or social justification for apartheid, CEDAW (in contrast to the earlier 1994 Declaration on the Elimination of Violence Against Women) fails to include a specific provision ruling out culture-based justification for gender discrimination – the primary source for such discrimination (CEDAW 1979; UN 1984; Mayer 2000–2001, 270–271). CEDAW unwittingly created a "loophole" allowing discriminatory practices.

More troubling, CEDAW provided states with an opportunity to create discriminatory customary law. In ratification and accession to CEDAW, a large number of states adopted reservations or understandings such that practices justified by custom or religion within their country are not deemed to violate the rights of women (Cook 1990). In accepting these declarations and reservations, the international community has allowed these states to establish legal precedent for their interpretation of the convention that supports their discriminatory practices (Clark 1991). Thus, in place of provisions that appear to unambiguously protect against any form of discrimination that would entail "any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women…of human rights…in the political, economic, social, cultural, civil or any other field," objecting countries have been allowed to assert interpretive understandings that substitute concepts such as "equilibrium and complementarity" for strict equality (Mayer 1995, 106). In lieu of the general interpretive rule for treaties under the Vienna Convention on the Law of Treaties requiring that a text be interpreted according to "the ordinary meaning to be given to the terms of the treaty…in light of its object and purpose," these reservations create an alternate interpretive frame shaped by the "context" under which the parties have accepted the convention (Vienna Convention on the Law of Treaties 1967).

RELIGION AND CULTURE

These efforts to limit or control the rights of women, though patriarchally based, are not justified by simple assertions of male privilege. Instead, countries frame the issue as a conflict between particular human rights values relating to women and the family, often described as Western and secular values, and competing values of culture and religion. While religion is frequently identified as the most serious threat to women's human rights, culture also serves as an equally significant obstacle (Okin 1999; Kessling and Sippel 2001–2002; Susskind 2004). Moreover, the two share many of the same bases for argument.

First, insofar as these issues generally reflect conflicts between the Developed and the Developing world, many people view them as residuals of colonialism in which the colonial West continues its efforts to dominate and control the rest of the world. Whether expressed as an attack upon native values or their religion, critics cite a long history of colonial repression (Mutua 1999). Commentators assert that resistance to Western models of women's equality, in this light, embodies a rejection of cultural imperialism and an expression of their own cultural nationalism (Mayer 2000–2001).

Complicating this conflict, religion and culture are not simply competing social values, they are themselves recognized as human rights. The right to freedom of conscience and religion, found in the Universal Declaration, and reaffirmed in the ICCPR (Art. 18), the IESCR (Art. 13(3)), and subsequent specialized treaties, such as the Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief (1981), is among the most widely recognized of the fundamental freedoms; with explicit precursors in the American Bill of Rights (1792) and the French Declaration of the Rights and Freedoms of Man (1789). Indeed, as early as the late 1700s, Thomas Jefferson identified religious freedom as the first and pre-eminent human right (Jefferson 1776).

Cultural rights, of the type represented in these conflicts, are of more recent origin. Often referred to as second or third generation rights, cultural rights nonetheless appeared as early as in the enactment of the ICESCR (ICESCR 1966). Even greater attention to the issue of cultural rights, in the form of people's rights, emerged with the creation of the African Charter on Human and Peoples' Rights in 1981 (Organization of African Unity [OAU], 1982), and the relativist challenge offered by the Bangkok Declaration (Peerenboom 2000).

Whether justified by religion or culture, the consequences for women's human rights and more particularly for women's health rights are equally grim. Based upon their positions relative to men, women are denied access to health care, face violence (including threats of death) and the dangers of unwanted pregnancies.

STRATEGY FOR CHANGE: THE HIERARCHY OF RIGHTS APPROACH

The most popular approach to overcoming religious and cultural resistance to women's human rights has been an argument based upon a hierarchy of rights. Specifically, women's advocates have argued that in the event of a conflict between women's rights and other values, women's rights should prevail (Meron 1986b; Charlesworth 1999; Doppelt 2002). This is the approach taken in CEDAW. Under CEDAW, state parties are to undertake "by all appropriate means and without delay [policies of] eliminating discrimination against women….by any person, organization, or enterprises… [including those embodied in] existing laws, regulations, customs and practices" (CEDAW 1979, Art. 2). State parties are to "take appropriate measures… [t]o modify the social and cultural patterns of conduct of men and women with a view to achieving the elimination of prejudices" and to reform education to eliminate "any stereotyped concept of the roles of men and women" (CEDAW 1979, Art. 5; CEDAW 1979, Art. 10).

Despite the obvious failures in its implementation, the approach taken in the text of the convention clearly justifies intruding upon, if not overruling, religious practices deemed discriminatory to women (Smolin 1995–1996, 152–156). For example, a parent's right to educate their child exists not only as a basic human right protected under the Universal Declaration of Human Rights and the ICECSR, for many it also reflects an aspect of religious freedom (Pierce v. Society of Sisters 1924; ICESCR 1966, Art. 13(3); UDHR 1948, Art. 26(3)). Indeed, the ICECSR asserts that it is the right of parents "to choose for their children schools, other than those established by the public authorities…to ensure the religious and moral education of their children in conformity with their own convictions" (UDHR 1948, Art. 26(3)). A strict interpretation of CEDAW, with an expectation that it take precedence, could overturn this right. For example, in interpreting a provision of the Convention on the Rights of the Child similar to the non-discriminatory educational mandate in CEDAW, a study by the American Bar Association concluded that private fundamentalist Christian schools teaching that (fundamentalist) Christianity was the only true religion would constitute a violation of the Convention (A.B.A., 1990).

Indeed, in a direct challenge to religious advocates, CEDAW specifically took on the challenge of reproductive rights. Controversy over the provision and protection of reproductive rights represents the most public and acrimonious battle ground between religious leaders and women's rights advocates. Countless commentators have attacked the Catholic Church and Muslim leaders for their opposition to abortion and various types of family planning (Weigel 1995, 24–31; Kessling and Sippel 2000–2001; Mayer 2000–2001, 290–319). In the face of this controversy, CEDAW provides for a woman's absolute right to "access to health care services, including those related to family planning" (CEDAW 1979, Art. 12(1) (emphasis added)).

There are numerous problems with this approach. They include legal weakness, foundationalist challenges, and historical conflicts based on colonialism.

Legal Weakness. While popular, the idea of recognizing and/or establishing a hierarchy among conflicting human rights has little support in international human rights law (Meron 1986a). International human rights law is neither a comprehensive nor a coherent undertaking. It is embodied in a wide range of international treaties and instruments (both UN based and regional) few of which attempt to provide a hierarchical valuation for the rights protected by them (ICCPR 1966, Arts. 4(1)–(2)). Nor are there comprehensive juridical structures designed to adjudicate rights disputes among the various sources of human rights law. Enforcement mechanisms for human rights are generally treaty or convention specific, such as the Human

Rights Committee of the ICCPR and the United Nations Economic and Social Council charged with enforcing the ICECSR (ICESCR 1966, Arts 16–25; ICCPR 1996, Arts 28–46).

In theory, CEDAW itself could provide legal precedent for the primacy of women's rights. Under the Vienna Convention on the Law of Treaties, conflicts between the provisions of successive treaties with respect to the same subject matter are to be governed according to which occurred later in time (Vienna Convention 1967, Art. 30(3)). However, as previously noted, while CEDAW provides interpretive justification for supremacy, it fails to explicitly articulate its hierarchical relation to religion and culture (Mayer 2001–2002). Even more damning, in allowing a significant number of reservations and understandings to the Convention to stand, proponents allowed for the creation of an interpretive context that made the rights set forth in CEDAW subservient to religious and cultural understandings (Cook 1990; Clark 1991). Thus, international law largely fails to support a hierarchical understanding of women's rights.

Foundationalist Challenge. In asserting the primacy of women's rights under CEDAW, advocates fail to justify that primacy. They therefore invite foundationalist and relativist challenges. Why should these rights take precedence over other important rights such as those of culture and religion?

In addressing the foundationalist or relativist challenge, many advocates adopt intuitive or syllogistic arguments. For example, in general terms, many advocates argue that human rights are obvious characteristics of the human. All humans are adverse to pain and suffering – therefore human rights respecting the prevention of torture or respecting the sanctity of life reflect not just Western or culturally contingent values but universal human norms (Dworkin 1986). As suggested by David Little, we all know that torturing little children for pleasure is wrong and that the child should have a right not to be tortured (Little 1993). Alternately, these advocates point out that the most vociferous advocates of relativism who challenge the application of human rights as a Western construct represent governments or regimes that are notoriously repressive and antagonistic to human rights and freedoms (Donnelly 2003).

The problem with the intuitive argument in this case is that it simply eludes the basic problem of the argument. While it may be accurate in grounding human rights in the nature of the human condition, it fails to respond to the question of how to resolve conflicts between different rights. There are no intuitive means of establishing a hierarchy of rights. For example, many might identify the right to life as the most fundamental and basic of all human rights. After all, the very existence of rights rests upon the ontology of the living human being capable of exercising and enjoying human rights. However, ample evidence exists that many people reject the right to life as an absolute. Jehovah's Witnesses, when confronted with a choice between receiving a life-saving blood transfusion as an element of medical treatment and violating their religious duties (thereby risking eternal life), overwhelmingly reject accepting blood transfusions (Dixon 1988). Even more common, many advocates for dying patients urge the legalization of euthanasia on the grounds of respecting human dignity as opposed to supporting an abstract standard of life at all cost (Dworkin 1994). For these people, the right to life is not an ultimate or absolute right when balanced with others.

Some may argue that a distinction should be drawn between the exercise of autonomous choice, illustrated by the Jehovah's Witnesses and victims of voluntary euthanasia/assisted suicide, and socially imposed violations of the right to life. For example, in the United States, many states usurp parental control over the health care of minors where the parent's beliefs may result in physical harm to the health of that child (State of Wash. v. King County Hosp. 1968). However, while such a decision represents a judgment about the competing value of particular rights conflict (i.e. the religious freedom rights of the parents versus the health rights of the child), it does not establish the primacy of the right to life as an absolute. Even where the balancing of rights or values is not based on autonomous choice, societies have never treated the right to life as absolute. Not only has it been subject to retributive justice (i.e. through the imposition of the death penalty) every country asserts the right to demand the potential sacrifice of its citizen's life in the defense of the nation – either in the military or the police (Selective Draft Law Cases 1918). Such sacrifice is not only justified by the state, it is honored by the public at large.

The syllogistic argument, the attacking the human rights bona fides of the critics of human rights, is even weaker. Beyond the logical fallacy of assuming that the character of an advocate necessarily impugns the arguments offered by that advocate, one cannot critique an adversary's opposition to particular human rights based upon their rejection of those human rights in practice. Indeed, the alternative for that adversary would be hypocritical – criticizing human rights but adopting them in practice.

History: Colonialism. Finally, in arguing for the primacy of women's human rights from the supposedly neutral position of international rights standards, many advocates fall prey to the charge of Western colonialism (Ahmed 1992; Benhaviv 1995; Al-Hibri 1999; Knop 2002). Even where the fundamental concept may indeed be universal, they fail to recognize the cultural contingency of how that concept finds expression. For example, many critics of the treatment of women in Iran cite the repressive character of dress codes for women that impose duties of modesty including specific features such as veiling. These critics fail to appreciate the fact that such dress codes can and do serve as a source of empowerment and politicalization for Iranian women (Halper 2003).

The colonialism criticism is valid insofar as it criticizes the effort to impose a Western interpretation of women's rights upon developing world countries, as opposed to supporting the expression of those rights within the cultural context of that country. Lacking absolute normative standards, the expression of rights may take multiple paths depending upon the social and cultural understandings of the values underlying those rights.

STRATEGY FOR CHANGE: THE POLITICS OF ENGAGEMENT

In recent years, a second approach to advocating for women's rights has emerged: one which starts with the premise that one must respect both religion and culture and women's rights. (Sunder 2003) Primarily led by women of faith within the cultural matrix in countries in which religion and culture has been used to justify limiting women's rights, these advocates seek not to reject the legal protection of religious freedom but to deconstruct the legal understanding of religion that uses religion as a shield for patriarchal discrimination (Sunder 2003). This strategy reflects both a principled idealism about human rights and religion combined with a pragmatic understanding of the human rights venture. Women are challenging the dichotomous choice presented by the hierarchy of rights strategy in favor of a synthetic approach to women's rights.

Principled Arguments: The Paradox of Liberalism. Human rights grew out of the fertile ground of liberalism. The premise of limited government, and the concept that individual humans have rights that transcend the power of the government, provide the fundamental support for the idea of human rights. In place of a world view which considered individual humans as subservient beings defined solely by their position in a hierarchical social order, liberalism argues for the primacy of the individual as the source of political legitimacy (Taylor 1995). With the fall of concepts such as the divine right of kings and lacking any persuasive alternative argument, governments throughout the world have resorted to justifications resting upon the authority and authorization of the people. Even despots and dictators talk about their governments as growing out of the will of the people (Ignatieff 2001; Donnelly 2003).

In this light, human rights are unavoidable adjuncts expressing the respect due to humans by virtue of their responsibility for political legitimacy. In a strict sense, rights are not creations of the state or gifts offered by its beneficence, but, rather, are aspects of the human condition. They recognize that humans, as the source of political sovereignty, would not surrender certain rights to the state. It is logically incoherent to suggest that individuals would create an instrument of governance that would deprive them of the conditions or characteristics that make them human.

While liberalism provides the grounds for protecting women, as human beings, liberalism also created the conditions that continue to repress them. Specifically, liberalism concentrates on the relationship between the individual and the state. It provides little guidance to those conditions that repress women. It is unable to address conflicts between individuals (other than the limited guidance of limiting rights which cause harm to others) or conflicts involving collectives (Guinn 2002). Instead, liberalism adopted the tactic of avoidance; it defined interpersonal conflict as falling within the private realm and outside of the public sphere with which it was concerned.

This tactic is particularly evident with respect to religion. Liberalism grew out of the Enlightenment and in response to the conflicts of the religious wars in Europe. In order to escape the dilemma of attempting to resolve religious conflict through political means, it simply side-stepped the issue by asserting that religion was a matter of private concern to be removed from the public realm. Viewing religion as irrational and organized religion as a threat to public government that would seek to utilize the power of the state to advance religious interests, liberalism simply drew a line promising to protect religion in the private realm against the state, provided that religion agreed not to interfere in the public realm. “The constitution of the modern state required the forcible redefinition of religion as belief and of religious belief, sentiment, and identity as personal matters that belong to the newly emerging space of the private (as opposed to public) life” (Asad 1993).

As now popularly recognized, the public-private distinction is not only illusory, it also creates conditions of oppression (Guinn 2002). Removing social practices of culture and religion from public view, such as women’s health and women’s place within the home and family, not only allows oppression to flourish, but also demonstrates the value of women’s contributions within those realms. It marginalizes women – itself a form of oppression (Young 1990).

Privatizing religion also invites problems. Indeed, “in an era of rising fundamentalism in which women’s – and men’s – lives are increasingly governed by private not public laws” the problem is of increasing urgency and significance (Sunder 2003, 1404). Legal efforts to relegate religion to the private realm has made “religion … the ‘other’ of international law” empowering it as a powerful counterweight to human rights (Sunder 2003, 1399).

The Challenge of Religion and Culture. While religion and culture can and often do present themselves as obstacles to women’s human rights, women do not stand outside their religions or cultures. Religion and culture are important to women as well as men. They contribute in varying degrees to a woman’s understanding of herself and constitute an element of her self-identity (Guinn 2002). To deny that aspect of personal identity denies the respect due to that individual as an equal member of society. In seeking to assert the primacy of women’s human rights over religion, hierarchy of rights advocates fail to respect the religious and cultural identity of those women who disagree with that hierarchical judgment. Indeed, hierarchical rights advocates, as a consequence of their evaluation of that religion, may create conditions that coercively separate the woman from her faith and culture. “Choosing rights over religion generally entails either leaving one’s community – literally seeking asylum elsewhere – or else praying that one’s culture becomes ‘extinct.’” (Sunder 2003, 1410–1411).

Instead of accepting this dichotomous choice, many Third World women argue that law must come to grips with religion. By treating religion and culture as the “other” outside the realm of law, it inadvertently empowers the entrenched patriarchy of religion. It fails to appreciate that religion and culture, like the public realm itself, is a contested territory. Religion is neither fixed nor univocal. It is subject to change and embodies many diverse understandings. The recurring question of women’s rights within religious communities around the world testifies to a “larger debate about democracy within religious communities” (Boyle and Sheen 1997). Law that ignores this internal conflict privileges the views of the existing authorities.

The Pragmatic Response. Understanding religion as "contested ground" does not promise the simple juridical answer that the hierarchy of rights approach attempts to provide. It demands political engagement. Fortunately, the potential for a women's health rights politics already exists. While the feminist scholarly literature is rife with ideological conflict and disagreement over questions of principle and theory, the movement has also demonstrated a significant level of pragmatism. Advocates who may fundamentally disagree on principles will nonetheless form alliances in advancing political agendas that promise to advance women's rights, even going so far as to adopt common strategies of discourse that promise tactical advantage (Riles 2001). This pragmatism was demonstrated, for example, in connection with the Beijing UN Congress on Women, where critics of rights discourse joined forces with other advocates to support the principle of "women's rights as human rights" where that approach was seen to promise significant rewards at the Congress (p. 207).

International women's health activists have demonstrated a similar pragmatism. Organizations such as Catholics for a Free Choice and the Women's Global Network for Reproductive Rights work both as international advocates for women's issues but also support local grass roots efforts around the world – many in countries whose governments have adopted religious-cultural justifications for their opposition to women's rights. This effort reflects an understanding that change cannot be imposed from without, but rather must come from within.

Illustrative of the problem of ideology and politics is a case of female circumcision/female genital mutilation that took place in Seattle, Washington. Female circumcision/female genital mutilation (FC/FGM) is a highly controversial practice of surgically altering the genitalia of female children. Experts estimate that as many as 120 million women have had this surgery, with between 4 and 5 million girls undergoing the procedure each year in 28 countries in northern and central Africa and in Muslim immigrant communities in the Philippines, Malaysia, Pakistan, Indonesia, Europe and North America (Guinn 2002). While most commonly associated with Muslims, it is also practiced by some Christians, animists and one Jewish sect (Guinn 2002). The practice has been politicized to such a degree that many activists disapprove of the use of the culturally sensitive term female circumcision as a misinterpretation of the practice. Such ideological fury, therefore, tends to mask the fact that the practice involves not one but a wide spectrum of practices ranging from Type I circumcision that involves very minor practices, such as pricking to draw blood or removing the clitoral hood or prepuce (a practice very similar to male circumcision) to Type 4 in which the clitoris, parts of the labia minora and labia majora are removed and the gaping wound to the vulva is stitched together, often leaving only a small opening for urine and menstrual flow. Type 4 also requires ongoing maintenance. The scar tissue covering the vulva must be cut to allow child-birth and resewn following child-birth to maintain its character (Kopelman 1994; Althaus 1997; Guinn 2002).

In the 1990s, a large numbers of Somalis, a country where FC/FGM is widely practiced, began immigrating to the area around Seattle, Washington. Doctors and nurses at Harborview Medical Center in Seattle soon found that pregnant Somali women, when asked if they wanted their new born sons to be circumcised, responded "Yes, and also if it's a girl" (Brune 1996, 1). Moreover, the parents of some Somali adolescent girls approached their doctors with a similar request to circumcise their daughters. They asserted a variety of reasons for seeking to have their daughters circumcised, including religion and culture.

In 1996, in response to these requests, Harborview doctors and administrators held a number of public meetings with members of the Somali community. During the course of these meetings they discovered two important facts. First, the Somali family members were amenable to accepting a form of circumcision far less intrusive than the Type 4, pharaonic FC/FGM practiced in Somalia. Indeed, the suggestion that the doctors perform a symbolic cut, a tiny bloodletting (necessary to satisfy the traditional demands of the procedure) under hygienic conditions with no foreseeable consequences originally came from the Somali women themselves (Davis 2001). This was a practice adopted by anti-FGM activists in Somalia (Obiora 1997). Second, the doctors also learned that many of these Somali parents, if denied access to a medically provided FC/FGM would find other means to achieve their goal, either returning to Somalia or enlisting the services of an immigrant Somali practitioner who would almost certainly perform a pharaonic circumcision in less than hygienic circumstances. (Davis, 2001)

Given these findings, Harborview announced that it would begin to offer a form of symbolic circumcision, involving a tiny nick on the prepuce which would be performed with appropriate pain medication and under hygienic conditions – a procedure closer to ear piercing than the circumcision procedure carried out on male children (Davis 2001). Unfortunately for these young girls from Somalia, the public outrage generated by this announcement ultimately forced Harborview to revoke this policy, condemning an unknown number of children to undergo the traditional practice. Opponents of FC/FGM, such as Patricia Shroeder, co-author of the United States law prohibiting any surgical alteration of the female genitalia articulated an uncompromising, hierarchy of rights approach (P.L. 104–208, Sec. 645(b), 110 Stat. 3009 (18 U.S.C. 116 et. esq.)). For these advocates, religion and culture are irrelevant concerns that must surrender to competing claims to protect women – even where such protective efforts may lead to greater harm in individual cases.

The Seattle/Harborville situation demonstrates the continuing dominance of the hierarchy of rights approach in the West – particularly the United States. Nonetheless, it also illustrates how a pragmatic, political solution could have addressed both the concern of protecting the health of the affected female children and the cultural/religious interests of those children and their parents. A critical literature is beginning to arise recognizing the virtues of the pragmatic/political response (Obiora 1997; Coleman 1998; Davis 2001; Shachar 2001; Platt 2002).

CONCLUSIONS: THE NEED FOR A SYNTHETIC UNDERSTANDING OF RIGHTS

Advocacy based upon a hierarchy of rights is ultimately doomed to failure. There are no legitimate, uncontested sources by which to identify such a hierarchy, nor are there inherent rationales within rights discourse capable of answering this simple question: Why prefer one right over another? The effort to impose an arbitrary hierarchy not only fails to persuade – it provokes resistance. It not only fails to respect the rights of the faithful, by its direct attack on religion that asserts that religion is subservient to a particular interpretation of women's rights, it fails to respect the religious and cultural rights of the women it seeks to protect. Finally, it falls prey to the legitimate critique that it reflects the continuing presence of cultural colonialism. Instead of treating these cultures and religions as human activities due significant respect, they are mistakenly portrayed by activists as monolithic sources of oppression, These activists fail to perceive those characteristics of religion or culture that embody particular values for the members of that faith or culture. In turn, those values must be weighed in balancing the interests of particular understandings of women's rights with the competing interests that women, as well as men, may have in preserving or protecting their religion or culture.

More fundamentally, the hierarchy of rights approach fails because it misconceives the human rights venture itself. Human rights and human rights law is not a simple juridical process. While it shares some of the indicia of a national legal system, such as legal instruments that identify specific rights and enforceable duties (i.e. laws) and enforcement mechanisms for those duties, such as the Human Rights Committee of the ICCPR (e.g. courts), compliance with the demands of human rights laws are predominately dependant upon state compliance (ICCPR Art. 28; An-Na'im 1994). Even those efforts that seek to adjudicate conflicts between religion and human rights through a juridical balancing of interests fail, not only by in effect deferring the question of a hierarchy of rights to later stage in the attempt to resolve conflict, but also because they presume the existence of some type of forum capable of making an enforceable judgment (Sullivan 1992).

While international human rights law serves the valuable purpose of shaping and framing the discourse on human rights, human rights are ultimately creatures of national law and politics (Ignatieff 2001). To be enforceable, those rights must be implemented and enforced by the states. Indeed, in talking about women's health rights, we are not simply talking about "negative rights" easily adopted by the states by refraining from some action; they require state action to implement them (Berlin 1969). It is not enough to assert that a woman has reproductive rights; resources must be committed to effectuate those rights. In doing so, politics determines issues of resource allocation among the many worthy endeavours of the state. Thus, political engagement by the women affected by these state allocations remains the most valid and valuable means of achieving change.

Advocating for a political solution in which competing rights are balanced and a synthetic result is achieved is not a call to relativism. It does not deny the universalism of basic human rights and values. Instead, it recognizes that while human rights may express fundamental human values, how those values are ranked relative to each other and how they are expressed in practice may vary (Mushkat 2002). Moreover, it grows out of the core value of human rights: the need to respect the human dignity of all persons. By engaging with religious advocates, we respect the choices of those others – including women of faith – even though we may disagree with their choices. Human rights simply command that we engage honestly in the debate in seeking ever enhanced protection for women's health.

Finally, the call to engage religion in the human rights project not only grows out of the recognition of religion as a human right, it recognizes the power of religion – for good or for ill – to affect human rights. Many critics have noted the role religion has had in oppressing women (Mayer 1995; Kessling and Sippel 2002; Susskind 2004). To overcome such opposition it is necessary to engage religion. Insofar as religions are the primary source of values for most people throughout the world, failing to engage or recognize the role of religion invites resistance (Childress 2000; Carter 2000). However, while religion may be a source of resistance, historically religion also has demonstrated its capacity to affect positive social change, such as in the abolitionist and civil rights movement in the United States (Guinn 2002). Religion can be a powerful agent of change because it "can easily reach where the State cannot – within the confines of the home" (Packer 2002). Failure to constructively engage religion as a potential partner in reform surrenders one of the most powerful instruments for social change to the forces resisting women's human rights. That would be folly.

REFERENCES

Adler, N. et al. (1999) Socioeconomic Status and Health: The Challenge of the Gradient. In Mann, J.M. et al. (eds.), Health and Human Rights: A Reader. New York: Routledge.

Ahmed, L. (1992) Women and Gender in Islam: Historical Roots of a Modern Debate. New Haven: Yale University Press.

Al-Hibri, A. (1999) Is Western Patriarchal Feminism Good for Third World Minority Women? In Okin, S. M., et al. (eds.), Is Multiculturalism Bad for Women? Princeton: Princeton University Press.

Althaus, F. A. (1997) Female Circumcision: Rite of Passage or Violation of Rights? Family Planning Perspectives, (Sept) 3 (1997) retrieved Oct. 27, 2005 from http://www.agi-usa.org/pubs/journals/2313097.html.

American Bar Association Centre on Children and the Law (1990) Children's Rights in America: UN Convention on the Rights of the Child compared with United States Law. (Cohen, C.P. & Davidson, H.A. (eds.)). Chicago, IL: American Bar Association.

American Medical Association Council on Ethical and Judicial Affairs. (1991) Gender Disparities in Clinical Decision Making, 266 JAMA 559, retrieved from http://www.ama-assn.org/ama/upload/mm/369/ceja_report_031.pdf.

An-Na'im, A.A. (1994) State Responsibility Under International Human Rights Law to Change Religious and Customary Laws. In Cook, R.J. (ed.), Human Rights of Women: National and International Perspectives. Philadelphia: University of Pennsylvania Press.

Asad, T. (1993) Genealogies of Religion: Discipline and Reasons of Power in Christianity and Islam. Baltimore: Johns Hopkins University Press.

Bassiouni, M.C. (2003) Lecture at the Specialization Course in International Criminal Rights, International Institute for the Higher Studies of Criminal Science. Siracusa, Italy, 09/8/2003.

Benhaviv, S. (1995) Cultural Complexity, Moral Interdependence, and the Global Dialogical Community. In Nussbaum, M.C. & Glover, J. (eds.), Women, Culture, and Development: A Study of Human Capabilities. Oxford: Clarendon Press; New York: Oxford University Press.

Berlin, I. (1969) Four Essays on Liberty. New York: Oxford University Press.

Boyle, K. & Sheen, J. (eds.) (1997) Freedom of Religion and Belief: A World Report. London. New York: Routledge.

Brune, T. (1996) Refugees' Beliefs Don't Travel Well; Compromise Plan on Circumcision of Girls Gets Little Support. CHI. TRIB., Oct. 28, §1, at 1.

Carter, S.L. (2000) God's Name In Vain. New York: Basic Books.

Charlesworth, H. (1999) The Challenges of Human Rights Law for Religious Traditions. In Janis, M.W. & Evans, C. (eds.), Religion and International Law. The Hague; Boston: Martinus Nijhoff Publishers.

Childress, J. (2000) The Challenges of Public Ethics: Reflections on NBAC's Report. Hasting Center Report, 27(5) 9–11.

Clark, B. (1991) The Vienna convention: Reservations, regime and the convention on discrimination against women. American Journal of International Law, 85, 285–321.

Coleman, D.L. (1998) The Seattle compromise: Multicultural sensitivity and Americanization. Duke Law Journal, 47, 717–83.

Cook, R. (1990) Reservations to the convention on the elimination of all forms of discrimination against women. Virginia Journal of International Law, 30, 643–716.

Cook, R. (ed.) (1994) Human Rights of Women: National and International Perspectives. Philadelphia: University of Pennsylvania Press.

Cook, R. & Maine, D. (1987) Spousal veto over family planning services. American Journal of Public Health, 77, 339–334.

Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. G.A. Res. 39/46, U.N. GAOR, 39th Sess., Supp. No. 51, at 197, UN Doc. A/39/51 (1984).

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, UN Doc. A/34/46 (1979).

Convention on the Prevention and Punishment of the Crime of Genocide, approved for signature Dec. 9, 1948, 78 U.N.T.S. 277.

Davis, D.S. (2001) Male and female genital alteration: A collision course with the law? Health Matrix: Journal of Law and Medicine, 11, 487–570.

Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief. G.A. Res. 36/55, 36 U.N. GAOR Supp. (No. 51) at 171, U.N. Doc. A/36/684 (1981).

Dixon, J.L., (1988) Blood: Whose choice and whose conscience? New York State Journal of Medicine, 88, 463–64.

Donnelly, J. (2003) Universal Human Rights in Theory and Practice. London: Cornell University Press.

Doppelt, G. (2002) Illiberal cultures and group rights: A critique of multiculturalism. In Kymlicka, Taylor, and Nussbaum. Journal of Contemporary Legal Issues, 12, 661–92.

du Guerny, J. and Sjoberg, E. (1999) Interrelationship Between Gender Relations and the HIV/AIDS Epidemic: Some Possible Considerations for Policies and Programs. In Mann, J.M. et. al. (eds.), Health and Human Rights. Retrieved May 15, 2004 from http://www.hsph.harvard.edu/fxbcenter/V1N1mannetal.htm.

Dworkin, R., (1984) Rights as Trumps. In Waldron, J. (ed.), Theories of Rights. Oxford/NewYork: Oxford University Press.

Dworkin, R. (1986) Report from Hell. New York Review of Books, July 17, 16.

Dworkin, R. (1994) Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom. New York: Vintage Books.

French Declaration of the Rights of Man and Citizen, August 27, 1789.

Geneva Convention. 75 U.N.T.S. 287 (August 12, 1949).

Guinn, D.E. (2002) Faith on Trial: Communities of Faith, the First Amendment, and the Theory of Deep Diversity. Latham: Lexington Books.

Halper, L. Negotiations of law and gender: Living shari'a in Iran. Washington & Lee Public Law and Legal Theory Research Paper Series, SSRN Network. Downloaded Oct. 2003 from http://ssrn.com/abstract=453523.

Howland, C.W. (1997) The challenge of religious fundamentalism to the liberty and equality rights of women: An analysis under the United Nations charter. Columbia Journal of Transnational Law 35, 271–377.

Iacopino, V. et al. (1998) The Taliban's War on Women: A Health and Human Rights Crisis in Afghanistan. Retrieved Oct. 15 2004 from Physicians for Human Rights at http://www.phrusa.org/research/health_effects/afghan2.html.

Ignatieff, M. (2001) Human Rights as Politics. In Guttman, A. (ed.), Human Rights as Politics and Idolatry. Princeton and Oxford: Princeton University Press.

International Convention on the Elimination of All Forms of Racial Discrimination opened for signature Dec 21, 1965, 660 U.N.T.S. 195.

International Convention on the Suppression and Punishment of the Crime of Apartheid. G.A. Res. 3068, U.N. GAOR, 28th Sess., Supp. No. 30, U.N. Doc. A/9030 (1973) art. II (a)(ii).

Jefferson, T. (1776) Virginia Statute for Religious Freedom, adopted January 16, 1786 available at http://usinfo.state.gov/usa/infousa/facts/democrac/42.htm .

Kessling, F. and Sippel, S. (2002). Women under oppressive regimes: Women and religious fundamentalisms. Conscience (Winter 2001/2002) Retrieved Jan. 10, 2004, from http://www.cath4choice.org/conscience/archived?oppressedRegimes.htm.

Knop, K. (2002) Diversity and Self-Determination in International Law. Cambridge New York: Cambridge University Press.

Kopelman, L.M. (1994) Female circumcision/genital mutilation and ethical relativism. Second Opinion, (Oct), 55–71.

Little, D. (1993) The Nature and Basis of Human Rights. In Outka, G. & Reeder, J.P. (eds.) Prospects for a Common Morality. Princeton: Princeton University Press.

Mann, J.M., Gostin, L., Gruskin, S., Brennan, T., Lazzarini, Z., & Fineberg, H.V. (1994) Health and human rights. Health and Human Rights 1. Retrieved May 15, 2004 from http://www.hsph.harvard.edu/fxbcenter/V1N1mannetal.htm.

Mayer, A.E. (1995) Rhetorical Strategies and Official Policies on Women's Rights: The Merits and Drawbacks of the New World Hypocrisy. In Afkhami, M. (ed.), Faith and Freedom: Women's Human Rights in the Muslim World. Syracuse: Syracuse University Press.

Mayer, A.E. (2000–2001) A "benign" apartheid: How gender apartheid has been rationalized. UCLA Journal of International Law & Foreign Affairs,5, 237–338.

Meron, T. (1986a) On a hierarchy of international human rights. American Journal of International Law, 80, 1–23.

Meron, T. (1986b) Human Rights Law-Making in the United Nations. Oxford: Clarendon Press.

Mushkat, R. (2002) Culture and international law: Universalism v. relativism. Singapore Journal International & Comparative Law, 6, 1028–1042.

Mutua, M. (1999) Limitations on religious rights: Problematizing religious freedom in the African context. Buffalo Human Rights Law Review, 5, 75–105.

OAU Doc. CAB/LEG/67/3 rev. t, 21 I.L.M. 58 (1982) entered into force Oct. 21, 1986.

Obiora, L.A. (1997) Bridges and barricades: Rethinking polemics and intransigence in the campaign against female circumcision. Case Western Reserve Law Review, 47, 275–378.

Okin, S.M. (1999) Is Multiculturalism Bad for Women? In Okin, S.M., et. al., Is Multiculturalism Bad for Women? Princeton: Princeton University Press

Packer, C.A. (2002) Using Human Rights to Change Tradition: Traditional Practices Harmful to Women's Reproductive Health in sub-Saharan Africa. Antwerpen; New York: Intersentia.

Peerenboom, R. (2000) Human rights and Asian values: the limits of universalism. China Review International, 7, 295–320.

Physicians for Human Rights. (1999) Report: The Taliban's War on Women: A Health and Human Rights Crisis in Afghanistan. Retrieved Oct. 2004 from http://www.phrusa.org/research/health_effects/exec.html.

Pierce v. Society of Sisters, 268 U.S. 535 (1924).

P.L. 104–208, Sec. 645(b), 110 Stat. 3009 (18 U.S.C. 116 et. esq.).

Platt, J.A. (2002) Female circumcision: Religious practice v. human rights violation. Rutgers Journal of Law & Religion 3, retrieved October 15, 2004 from http://www.camlaw.rutgers.edu/publications/publications/law-religion/JVol3.htm.

Riles, A. (2001) The Case of "Women's Rights are Human Rights." In Likosky, M. (ed.), Transnational Legal Processes. London: Cambridge University Press.

Sachar, A. (2001) Multicultural Jurisdictions: Cultural Differences and Women's Rights. Cambridge; New York: Cambridge University Press.

Selective Draft Law Cases (1918) 245 U.S. 366.

Smolin, D.M. (1995–1996) Will international human rights be used as a tool of cultural genocide? The interaction of human rights norms, religion, culture and gender. Journal of Law & Religion, 12, 143–171.

State of Wash. v. King County Hospital (1968) 390 U.S. 598.

Sullivan, D.J. (1992) Gender equality and religious freedom: Toward a framework for conflict resolution. N.Y.U. Journal International Law & Policy, 24, 795–856.

Sunder, M. (2003) Piercing the veil. Yale Law Journal 112, 1399–1472.

Susskind, Y. (2004) Women's health in a sick world. Madre. Retrieved Mar. 9, 2004 at http://www.madre.org/art_whSickWorld.html.

Taylor, C. (1995) Multiculturalism and "the Politics of Recognition." Reprinted in Philosophical Arguments. Cambridge; London: Harvard University Press.

United Nations Statistics Division. Retrieved Jan.2004 from http://unstats.un.org/unsd/demographic/ww200pr.htm.

US. CONST. amend. I (ratified 1792).

US. Department of State Bureau of Democracy, Human Rights, and Labour. (1999) Country Reports on Human Rights Practices: Saudi Arabia. Retrieved Feb. 25, 2000 at www.state.gov/www/global/human_rights/1999_hrp_report/saudiara.html

Vienna Convention on the Law of Treaties, enforced, Oct. 4, 1967, Art. 31(1)(2), 606 U.N.T.S. 267.

Weigel, G. (1995) What really happened in Cairo. First Things, 24–31.

World Health Organization (1946) Constitution of the World Health Organization (July 22, 1946) Retrieved from www.opbw.org/int_inst/health_docs/WHO-CONSTITUTION.pdf.

Young, I.M. (1990) Justice and the Politics of Difference. Princeton: Princeton University Press.

PART II

THE CENTRALITY AND LIMITS OF AUTONOMY

JACOB D. RENDTORFF

CHAPTER 6
THE LIMITATIONS AND ACCOMPLISHMENTS OF AUTONOMY AS A BASIC PRINCIPLE IN BIOETHICS AND BIOLAW

The principle of autonomy is proposed as a very basic and universal principle in bioethics and biolaw. In the following paper, I will examine the limits and possibilities of the idea of autonomy in order to see to what extent we need to accompany autonomy with other principles in order to develop a European bioethics and biolaw. It will become clear that autonomy is not the only principle and that it is limited in the extent it is applied in bioethics. My argument attempts to show the limitations of autonomy by relating it to other concepts. It will be suggested that autonomy is a necessary and useful concept that, however, remains an ideal notion in relation to ordinary medical practice in bioethics and biolaw.

I argue that autonomy must be amplified by other principles or regulating guidelines if it is to be adequately applied in bioethics and biolaw. Autonomy helps us to focus on human rights and respect for human persons as the central concern in bioethics; but it is not sufficient to provide the required protection in many limit-situations of health care. In order to fully understand the significance of autonomy we have to consider autonomy from the perspective of other important values and principles. These other ideas, which I have discussed in more detail elsewhere (Rendtorff and Kemp 2000) are the principles of dignity, integrity and vulnerability. Together with autonomy, these principles help to define the necessary concern for the human person in bioethics and health care ethics. Before I go on to elaborate autonomy in detail I will turn to a brief definition of these principles, considering their relevance for the limitations and possibilities of autonomy.

A philosophy of the basic ethical principles – autonomy, dignity, integrity and vulnerability – provides a normative framework for the protection of the human person in biomedical development (Sève 1994). The central question is: “What do we want humanity to be like?” As a guideline in bioethics and biolaw, the concept of autonomy expresses our wish to provide humanity and the human person with the necessary protection in these fields. The principle of autonomy contributes to the expression of the political morality of the medical and legal systems in modern society. In connection with the ideas of dignity, integrity and vulnerability, autonomy can be said to articulate the protection of a human person’s “privacy” in the face of technological developments. In this way these principles can be understood as the foundation of a human rights policy, which is the case in most European countries. Combined with the ideas of dignity, integrity and vulnerability, the principle of autonomy can be extended to other fields of legal practice, such as

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 75–87.

social law and administration. Indicating respect for persons as ends-in-themselves in a European legal culture, the application of these principles in bioethics and biolaw reflects the cultural differences and local variations in Europe (Häberle 1997). Such a cultural regionalism is built on the idea of "subsidiarity," meaning that interpretations and decisions about ethics and law should respect the cultural differences of different European countries. Accordingly, we should give room for each European state to make use of the principles according to the particularity of their specific convictions.

My argument, however, is that dignity cannot be reduced to autonomy. Rather, the concept of dignity is defined both as having intrinsic value and as a matter for constructive morality in human relationship (Rendtorff and Kemp 2000). It expresses the outstanding position of human beings in the universe. It refers to the inviolability of individual human life. It further indicates the moral responsibility of the human person. This idea of dignity must be respected in the intersubjective relations of the Kingdom of ends-in-themselves. On this basis, human dignity has the following meanings as an intersubjective concept: (1) it expresses the intrinsic value of the human being in a community or society; (2) it includes respect for the moral agency of the human subject; (3) it means that every human being must be considered not to have a price and not to be an object of commerce; (4) it refers to the indeterminate position of human beings in the universe; (5) self-esteem, pride , shame, feelings of inferiority and degradation are essentially matters of human dignity expressed through intersubjective relations between individuals; (6) dignity can establish restrictions on interventions upon human beings in taboo-situations, because of the necessity of human civilized behaviour; and (7) dignity relates to metaphysical experiences of human beings in existential limit by degrading treatment. But the relation between rights and dignity is also essential (Rendtorff and Kemp 2000). In that context human dignity expresses the intrinsic worth and fundamental equality of all human beings.

The principle of integrity refers to the totality of life-emphasizing that it should not be destroyed. Integrity has a coherence that in a certain sense must not be touched. This coherence or rather *Lebenszusammenhang* is the narrative coherence of a person's life (the lifestory) or the narrative (historical) unity of human culture (Rendtorff and Kemp 2000). On this basis, integrity has four meanings: (1) integrity as a narrative totality of wholeness, completeness; (2) integrity as a personal sphere of self-determination; (3) integrity as a virtue of uncorrupted character, expressing uprightness, honesty and good character; (4) integrity as a legal notion, where it expresses the moral coherence of the legal or medical system (Rendtorff and Kemp 2000). In bioethics and biolaw, the idea of integrity as an untouchable core, the personal sphere that should not be subject to external intervention, is the most important. The personal body must be considered from a phenomenological perspective of self-mastery of the body. Integrity expresses bodily completeness in a private sphere. In medicine this is indispensable for trust between physician and patient. There is a close link between respect for identity and respect for integrity where a personal narrative expresses the life context of the individual. In this way, respect for integrity is recognised as a right to privacy and constitutes the virtues of the legal and medical systems.

Vulnerability of psychic and corporeal life is closely linked to integrity. It does however express additional characteristics of the human condition (Rendtorff and Kemp 2000). Protection of vulnerability is considered as the bridging factor between moral strangers in a pluralistic society and therefore respect for vulnerability is essential for policy making in the modern welfare state. Although it is a very important concept, few scholars have looked carefully into its consequences for social responsibility (Goodin 1985). Vulnerability is not only a condition of the poor and weak in society. Vulnerability should be considered as a universal expression of the human condition; as an expression of our finitude and fragile humanity, vulnerability is the reason why we have ethics (Levinas 1961). Moreover, it appeals to protection of both animals and the teleological auto-organization of the world. However, vulnerability has been largely misunderstood in modern society, as it has been guided by a so-called "vulnerability reducing agenda," which attempts to eliminate all vulnerability, i.e. suffering, abnormality, deafness and disability, in order to create perfect human beings (Callahan 2000). Respect for vulnerability must find the right balance between this logic of a struggle for immortality and the finitude experienced through the earthly presence of human suffering.

Medicine relates to suffering as expressed by this twofold vulnerability. It is called upon to re-establish the natural balance of the human body and organism. It is both a normative science and an art, even though modern medicine has its basis in the physiology of the organism. It must refer to bodily vulnerability where the human person is both object body and living body. In this way, the art of medicine is guided by the application of basic ethical principles to the protection of the human person. Consequently, respect for vulnerability should be made more evident as the essential foundation of the treatment of human beings in hospitals and the legal system.

The basic ethical principles are promoted in the framework of solidarity and responsibility. This includes the idea of social progress toward a more developed society. These principles are an expression of the movement of society in the civilizing process toward the Kingdom of Ends. Their application corresponds to the integration of the principles in an ethics of care, based on protective responsibility and emotional care for vulnerable subjects (Held 1998). It is the task of this ethics to take care of civilization and secure the self-realization of human individuals in the welfare state. On this basis we may argue that human beings, as members of society, are not only participants in a social contract, but their lives and existence are considered as fundamental goods in the Kingdom of Ends. This involves protection of the idea of humanity and the inviolability of concrete human beings by integration into a collective responsibility for society.

To consider autonomy, dignity, integrity and vulnerability from the perspective of responsibility and solidarity introduces an ethical foundation for political and social human rights of human persons. Such a turn from a contractual to a protective concept of human rights provides protective rights for human beings and their bodies confronted with the new possibilities of biotechnological development such as cloning, reproductive technologies and genetic engineering. This shift in emphasis from contractual property rights to protective human rights is the current condition for the application of the principles in the different fields of biomedicine.

AUTONOMY AS A BASIC PRINCIPLE

On this basis, in order to give a more elaborate account of the concept of autonomy, it should be emphasized that the principle of autonomy in a modern pluralistic liberal society, as being the right to choose one's own way of life for oneself, is considered to be of supreme value (Charlesworth 1993, (1). The principle of autonomy is the principle of liberty (Kemp 2000). Autonomy consists of "auto" and "nomos." This means self-government in Greek, as in Ancient Greece a city-state was said to be autonomous when it was self-governing (Dworkin 1988, 12). People are considered to be autonomous to the extent that they are able to control their own lives and decisions, just as an independent government acts to control its policies (Beauchamp and Childress 1979, 68). In the Western tradition, autonomy has been linked to the freedom of the individual and the possibility of harmonious development of the human person according to personal choices, desires and wishes for his or her future life. The idea of a pluralistic society is that people as autonomous moral agents are free to choose for themselves, even if their choices are mistaken according to the opinion of the majority (Charlesworth 1993). Autonomy is a second-order capacity of individuals to reflect on their first-order preferences and desires (Dworkin 1988, 20). Thus it is important to stress that a theory of autonomy must include positive liberty and the active choices of the individual.

Consequently, five important meanings of autonomy can be put forward: (1) the capacity for the creation of ideas and goals for life; (2) the capacity of moral insight, "self-legislation" and privacy; (3) the capacity of rational decision and action without coercion; (4) the capacity of political involvement and personal responsibility, and (5) the capacity of informed consent to medical experiments, etc.[1]

A BRIEF HISTORY OF AUTONOMY

This constellation of ideas about autonomy is rooted in a long European history: Aristotle made a close connection between autonomy and voluntary action. A voluntary action must be freely chosen by the agent. Lack of outer restraint and intervention is fundamental to his concept of autonomy. For Immanuel Kant, the Enlightenment philosopher *par excellence*, the agent has moral freedom and is autonomous because it is an end-in-itself and as such has unconditional worth (Beauchamp and Childress 1979, 72). From this perspective a person is both his and her own moral legislator and agent. Autonomy indicates the ability of the human being to be a self-legislative rational being, having the capacity to recognize the universal validity of moral law without being determined by outer, heteronymous conditions for action (Hansson 1992). This autonomy means that human beings are different from animals and the natural world because of their capacity for moral autonomy. We take part in two worlds; the world of natural causality, as bodily incarnate beings, and the world of moral reason, as beings that participate in the world of reason. Our freedom does not consist in arbitrary choices of action, but in our "good will"; our capacity of acting in accord with moral reason.

This strong moralization of the idea of autonomy disappears in the liberal utilitarian philosopher John Stuart Mill, for whom autonomy is said to consist of the possibility of making our own actions and decisions without coercion. With John Locke and Thomas Paine, Mill is one of the initiators of the ideal of the rights of man and of personal autonomy as being central to liberal democracy. The freedom of the individual to choose his or her life in society is a political principle. An individual's personal liberty vis-à-vis the state should be as great as possible and paternalistic action should be avoided. In a liberal society there cannot be substantive agreement and consensus about fundamental life-styles and religious values (Charlesworth 1993). The only real substantive value is the recognition of individual, personal autonomy.

The intrinsic connection between autonomy, moral independence and personal self-development is also stressed in European personalistic and existential philosophies that emphasize personal freedom, engagement and responsibility for one's own life.[2] From an existentialist perspective, autonomy also includes a process of reflection and the active presence of the individual (Sartre 1943). Existential freedom is a condition for personal identity and self-development. Jean-Paul Sartre's philosophy of human freedom, where the human being is constantly choosing his or her own existence and life in basic autonomy, is an example of the process of self-creation and personal choice as essential to the concept of autonomy. But to Sartre, even though the human individual is free to choose his or her own existence, this condition is often hidden in an inauthentic life of self-deception. Perhaps a philosophy of existential authenticity can overcome the bad faith and self-deception that are so common in the life of the modern individual.

A POLITICAL NOTION OF AUTONOMY

For many people today, moral autonomy is a question of free moral choice according to a set of values determined by the individual to be right and just (Dworkin 1988, 34). To be morally autonomous is related to sincere choice and personal decision-making, rather than to the invention of genuinely personal values. The question is, however, whether autonomy includes a total, substantial and procedural independency or if, instead, it is possible to be autonomous and, at the same time, rely on shared values, the legal system and moral or religious authorities. This leads to the question of whether it is possible to act autonomously in situations where there exists a large degree of outer determination. Furthermore, in which way are autonomous decisions allowed to rely on the opinions of other persons? In this context it should be evident that moral autonomy is related to free and autonomous choice, but that this does not imply total independence from external factors.

As the political origins of the term "auto-nomos" suggest, there is a close relation between individual autonomy and the political organization of society (Dworkin 1977; Habermas 1992; Rawls 1992). In modern democratic society, the idea of justice presupposes that human individuals are "born free and equal" and that the maximum of freedom and fairness should be realized for everyone. According to this idea a just society is developed through a procedure of construction, whereas autonomous agents are supposed to have already agreed rationally on some common principles of justice. In this context it is important to stress that a society built on responsible, autonomous decision-making is not necessarily a society without communitarian engagements and common values.[3] But the choice of such values should be motivated by individual decision-making rather than collective coercion, without *a priori* excluding common decision-making.

A European concept of political democracy focuses, both, on the idea of autonomy (as inseparable from its relation to dignity, integrity and vulnerability) and on the "good life for and with the other in just institutions" (Ricoeur 1990). It is an essential feature of this ideal to recognize political society as a deliberative democracy, founded on respect for the political sphere and the democratic exchange of opinions among citizens, as the basis of common values. It is important in the vision of liberal democracy that the individual has the possibility of self-realization and of self-development. A legitimate government should be built on the self-determination of autonomous individuals. Therefore the protection of individual autonomy is a basic principle in most European constitutions. The importance of autonomy for the development of the human person (personal agency), political democracy and our conceptions of moral decision-making, are the background for the significance that is attributed to autonomy as a basic right that can be used to justify protection of privacy and claims of confidentiality.

In bioethics the principle of autonomy is primarily expressed in the concern for "informed consent" (Kemp 2000). However, informed consent as an essential feature of medical decision-making has, until now, been largely determined by the care for personal autonomy of the subject. It is also greatly discussed to what extent the requirement of informed consent can be generalized to the treatment of patients. Claims are made that the patient must have the right to make his or her own decisions concerning treatment and refusal of treatment. The concept of informed consent should be able to secure both a thorough-going self-determination of the patient undergoing medical treatment and that the patient has meaningful choice and freedom in relation to the process of medical treatment. In this context the essential elements of informed consent are (1) disclosure, (2) understanding, (3) voluntariness, (4) competence and (5) consent.

THE LIMITATIONS OF AUTONOMY

The principle of autonomy as a method of regulating bioethics and biolaw, however, is not without genuine difficulties. Generally, autonomy as a notion is an ideal, referring to the full self-control of the individual. But there may be defects in an individual's ability to control actions or desires, or both. The individual's capacity of reasoning may be limited or nonexistent, and this is not only the case for children, senile, insane persons etc, but also for normal, intelligent people who feel themselves weak and dependent on others, or who simply do not understand the scientific project in which they are asked to participate. The individual may also make decisions on the basis of inaccurate or false information, which can be gathered from many sources. Besides, the individual's desires or wishes may be confused. Personal identity is not always stable and the individual sometimes does not know what he or she really wishes (Harris 1984).

An important criticism of this ideal of the free and autonomous individual who can decide his or her own life, contends that it is very far from the medical reality of the clinic and the particularities of bioethics and biolaw. It is argued that mutual respect for autonomy does not offer an adequate framework to conceptualize the relationship between patient and physician. The criticism states that autonomy presupposes an individual with no social ties. It also presupposes, too strongly, the capacity of the individual to make his or her own decisions. In the extreme situations of medical treatment it is not likely that people can make independent and autonomous decisions. They are vulnerable, weak and not in control of the situation (Baum 1997). Furthermore, it is not likely that people in their ordinary life actually make independent and rational decisions without the intervention of other people. In fact, few decisions in extreme situations follow the requirement of personal autonomy.

Moreover, some people state that freedom and diversity are not the only absolute values. At times community life, built on common values, is a necessary condition for autonomy. In this context it is argued that the concept of autonomy presupposes an institutional and cultural background based upon the common value of respect for diversity and personal liberty. So an account of autonomy cannot be totally libertarian but should recognize that the individual is situated in a large number of social practices, commitments, compassions and relations to other people (Reich 1978, 219). To only focus on autonomy makes one forget the fragile and vulnerable components of the human condition requiring care and respect for the human person. But this account breaks with autonomy as the only justification of a liberal society and therefore a more elaborated concept of the protection of the human person is needed.

Along similar lines it has been advanced that the ideal of the autonomous self in ethics and politics is based upon an implausible idea of the "unencumbered self (Benhabib 1994).[4] It is argued that the prevailing concepts of autonomy are results of an abstract universalism that does not take into account the daily reality of human life. In this perspective autonomy is the wrong account of human existence because the individual is always situated in a multiplicity of contexts and life situations where dependency on others is very important. Besides, the narrative structure of personal identity, and of the experiences of the individual, shows that decision-making is always the result of the interactions of the individual with the social context. Human experience is embodied and our sense of identity and choice is embedded in social context. We are often in situations where we are in "bad faith" and unclear understandings of our own motives, emotions and actions limit our possibilities of rational decision making. The idea of the self as totally self-determinant and self-transparent is an abstraction from this reality of ambiguity and multiple senses of meaning which characterises the human life-world. Instead, the subject is constituted in concrete relations of gender and community. The situation of the subject is placed in a life-world, where the individual stands in relation to "concrete others" as in, for example, the family.

Consequently, the notion of autonomy cannot be the only concept utilized to express the ethics of biomedicine and the protection of human beings in the biomedical field. There are a number of difficulties that necessitate the integration of autonomy with other fundamental principles in bioethics and biolaw. First of all, the concept of autonomy cannot be abstracted from the vulnerable and fragile human condition and the existence of the person as a “situated subject.” It is not certain that the patient is able to judge the treatment process or fully understand the situation of treatment. Furthermore, the problematic of correct disclosure of information and of possible paternalist intervention by the doctor arises. The therapeutic privilege of the doctor in a situation where a piece of information would be of doubtful benefit to the patient is one example case. Moreover, one could mention moral traditions and conceptions at the hospital that are in conflict with the personal conceptions of the patients (Faden and Beauchamp 1986).

Apart from these internal difficulties of the principle of autonomy, there are situations in bioethics and biolaw where the principle simply does not apply. In cases concerning unborn life, embryos, the fetus, the human body and its body parts, the body after death, organs etc., and the principle of autonomy is of little significance because one cannot say that any of these have moral autonomy. This is true in particular for incompetent patients, e.g. minors, coma-patients or the mentally ill, who are not able to make their own decisions. We are reluctant, however, to think that these people have no moral value. Therefore the concept of autonomy is very limited when used as the only concept for the adequate protection of the human person. Other dimensions of the protection of individuals must be taken into account. Therefore, we must talk about such principles as dignity, integrity and vulnerability.

AUTONOMY AND THE PHYSICIAN-PATIENT ENCOUNTER

These limitations of the concept of autonomy can be seen in relation to the physician-patient encounter and the relation between individuals and the health care personnel. Here the concept of informed consent is proposed as the major feature. In many cases the medical act as such is an intervention upon the personal integrity, dignity and autonomy of a human being. Therefore respect for persons is essential to medical ethics and must be presupposed in the ethical and legal concept of informed consent. However, this concept is relatively new. In recent years there has been a shift from medical paternalism toward respect for the will and wishes of the patient as an independent moral agent. In understanding the relationship between health personnel and patients it is important to distinguish between bioethics and biolaw. This means that a “friendship model” based upon close encounters and prudential relationships between health care personnel and patients precedes the “contractual rights model” of biolaw. The first legal initiatives to regulate informed consent were made when a decree on medical experiments was passed by the last government in the German Weimar Republic in 1931 (Ambroselli 1988, 27). It stated that a fundamental criterion for medical experiments and treatment of human beings was the free and informed consent of the individual. Unfortunately, the Nazi regime completely ignored this decree in their horrifying experiments with human beings in the concentration camps. After the Nazi atrocities, the Nuremberg Declaration (1948) was the first of a number of International Declarations on the use of human beings in medical experiments. According to this Declaration, informed consent is a necessary, but not sufficient, condition for experiments. The experiment must also not cause the research subject permanent harm or damage. The Helsinki Declarations (Helsinki I and II) as a development of the Nuremberg Declaration were introduced by the World Organization of Physicians in Helsinki in 1964 and revised in 1975 in Tokyo. Helsinki II extends Helsinki I by proposing the establishment of Medical-Ethics committees in all countries. The fundamental idea in these declarations is that "the welfare of the individual shall prevail over the interest of science and society".

Today the concept of informed consent has been generalized and is now well established in many national and international codes of conduct (Delfosse 1993). That this was a new development can be shown by the fact that many physicians in the 1950s and 1960s considered patient autonomy a myth. The patient was not seen as possessing sufficient autonomic capacity to evaluate a treatment. The patient was not considered to be on the same level as the physician. He or she was, rather, like a child that needed paternalistic protection (Ambroselli 1988, 5). Although there is much value in this conception of the responsibility of physicians to their patients, there was also the criticism that physician paternalism did not adequately recognize the autonomy of the patient in relation to the treatment process.

This has now changed in many European countries. The therapeutic revolution has led to the multiplication of treatment options for the individual. Secularization processes in a pluralistic society with many different modes of life signify that bioethics and biolaw operate on a pluralistic basis with different worldviews and conceptions of the good life (Engelhardt 1987). The fact of value pluralism indicates that traditional paternalism cannot function and instead the ethical values of the patient should be integrated into medical treatment.

AUTONOMY AND PHYSICIAN AND PATIENT COMMUNICATION

In light of respect for the autonomy, integrity, dignity and vulnerability of the patient, it should be emphasized that a therapeutic dialogue is necessary prior to any application of the concept of informed consent. The relationship of care requires an existential and therapeutic conversation between physician and patient. Such a conversation can be defined as a "loving struggle" (Karl Jaspers 1919), openness toward the arguments of the other in the therapeutic relationship and a willingness to argue with and to respect the arguments of the other. Ideal communication is to be both critical and open toward the life horizon of the other human being. Communication is not the destruction of all conflict and opposition, but a critical dialogue of engagement with the other person. In this context the therapeutic dialogue can be defined as a two-way communication between the treatment team (physicians, nurses) on the one hand, and the patient and relatives on the other. The clinical situation of care is marked by an understanding of the existential situation of the person to be treated. Treatment is not a monological gaze of domination, it includes participation in the experiences of the patient within the specific situational context. Face to face with the patient the physician is directed toward understanding the patient's personal experiences in order to secure a good treatment. It is the task of the physician to reconstruct the narrative disease story of the patient, and to understand it in the horizon of his or her life story. In this way, the therapeutic relationship, in the context of autonomy that cannot be separated from other basic ethical principles, should be understood in the tension between the professional distance and personal participation of the physician in the life context of the patient.

Essentially the interaction between health personnel and patients, or the physician-patient relationship in general, can be considered as part of an individual's attempt to realize their vision of the "good life for and with the other person" (Ricoeur 1990). This is the basis of individual self-esteem and self-respect, where the idea of informed consent is interpreted in light of the person seen as an independent moral subject. The physician-patient relationship of informed consent deals with the problem of how to balance treatment, interest and consequences with respect for the human person. During the course of treatment, the physician should be aware of the wishes and the will of the patient to be informed of the course the treatment is taking. In order to facilitate treatment choices while maintaining respect for the identity and integrity of the patient, within their vision of the good life, the physician is responsible for offering the patient correct information about his or her condition. Mutual trust is a basic feature of the relationship between health personnel and patient. Trust is accepted vulnerability based upon a relational concept of autonomy.[5]

However, there is a strong asymmetrical relation between the vulnerable patient and the strong physician. The will of the patient might not be expressed adequately in informed consent. The patient's capacities of reasoning might be limited. There is also the problem of revealing information that will hurt the patient or revealing it in a way that will unnecessarily discourage the patient. Successful physician patient interaction needs good communication adapted to the concrete situation of the patient. Moreover, there might be problems of irrational wishes, differences between present and future wishes, change in the personality of the patient, pressure from outer forces and lack of self-understanding – the patient not knowing what he or she really wants. It is also doubtful if patients are capable of understanding the information that is given by physicians. Knowledge, insight and understanding are dependent on background knowledge and how the recipient receives it. But even if informed consent is possible it is determined by a number of deficiencies. The physician can inform the patient about objective aspects of a disease, but the existential aspects of the patient's experience of the disease are difficult to grasp.

Therefore, informed consent based upon the basic ethical principles should be considered as a more comprehensive notion than a formal agreement, or a "silent world" of mutual acceptance between patient and physician. Rather, it should be conceived as "a process of events," a communicative encounter where physician responsibility leads to disclosure, "voluntariness" and equality (Faden and Beauchamp 1993), built on respect for the other principles of the dignity, integrity and vulnerability of the patient.[6]

We should not forget that there might be cases where consent to treatment is degrading for the human dignity of the patient. There is both a subjective and an objective sense of degrading treatment, from the perspective of the physician and of the patient. Some degrading treatment is perhaps justified in order to secure the future health of the patient. It is important to make explicit the possible degrading treatment in the process of informed consent in order to avoid dissolution of personal identity leading to great personal problems as a result of being objectified by medical technology.

Medical treatment includes the risk of violating the individual's integrity. The medical act might not be possible without a bodily "objectification" of the person, which may also violate integrity. But it is only justified in order to restore the person's health, re-establish the corporeal balance of the individual and overcome the disease. Respect for the untouchable, for the completeness and wholeness of the patient, are integrated parts of the relation between health personnel and patients. Consequently there is some intervention in patient integrity that is welcomed as an important restoration of the patient's personal life totality.

Patient vulnerability is, likewise, an integrated part of the process of informed consent. It is an indication of the asymmetrical relation between physician and patient (Folshed 1997, 154). Paul Ricœur defines the patient/doctor relationship as a "*pacte de soin*"[7] a professional relationship of friendship, focusing upon the asymmetrical aspects of medical treatment. This leads to a necessary articulation between autonomy and vulnerability (Baum 1997). It is necessary to go beyond the opposition between patients' rights and patient vulnerability, between curing and caring, and instead focus on the situated subject as being both extremely vulnerable and having a will, wishes and desires. Patients should not be described as autonomous in the sense of an ethos of survival of the strongest that is particular to rights discourse (Baum 1997, 19–20). We should avoid becoming trapped in the alternative of de-responsibility of the health system in favor of liberal thinking. Informed consent should not make the patient more vulnerable.

The integration of not only autonomy, but also dignity, integrity and vulnerability as the foundation of the relationship between health personnel and patients expresses the idea of an asymmetrical relation to the other. It considers autonomy as situated, which makes it possible to take into account the vulnerability of the patient. The reason is that the experience of illness reveals that "the human subjectivity exists as a sensible affective, suffering, aging body, whose presence and proximity alone give meaning to the term vulnerability as limiting one's autonomy by revealing its finitude" (Baum 1997, 22). Critical examination of the relationship between health personnel and patients in the light of the basic ethical principles has been oriented toward a reinforcement of the concept of informed consent in the European formulation of patients rights, general medical law and deontology, where the physician generally has a duty to inform the patient, especially in situations of the therapeutic exception. In some cases family privacy in relation to medical secrecy is also important. Respect for persons, seen through the basic ethical principles, articulates the relationship between health personnel and patients as a communicative process (Nerheim 1994).

CONCLUSION

A crucial presupposition of the argument has been that the concept of autonomy is a major and important principle in bioethics and biolaw, while also remaining a very limited concept. The principle of autonomy should not only be interpreted in the liberal sense of "permission" given for treatment and/or experimentation. Five qualities are important to consider: (1) the capacity of creation of ideas and goals for life; (2) the capacity of moral insight, "self-legislation" and privacy; (3) the capacity of reflection and action without coercion; (4) the capacity of personal responsibility and political involvement; and (5) the capacity of informed consent. But autonomy cannot express the full meaning of respect for and protection of the human being. Autonomy remains merely an ideal, because of the structural limitations given to it by human finitude and dependence on biological, material and social conditions, lack of information for reasoning etc. We must recognize the human person as a situated living body. It has therefore been said that other principles such as the dignity, integrity and vulnerability of the patient should be taken into account in order to have a better understanding of the principle of autonomy. This is especially present in new interpretations of the Patient-Physician-Encounters as well as the communicative processes between patients and health care personnel in which care for the dignity, integrity and vulnerability of the patients is very important.

ACKNOWLEDGEMENTS

This chapter is based upon the Project Report “Basic Ethical Principles,” *Bio-Med II, 1995–1998* (2000) by Jacob Dahl Rendtorff and Peter Kemp. I thank Professor Kemp for his valuable work and comments to our common report, of which this chapter helps to express our results on the analysis of the principle of autonomy in bioethics and biolaw.

NOTES

[1] These five meanings sum up our account of the concept of autonomy in the EU-project (Rendtorff and Kemp 2000).

[2] Isaiah Berlin has, in some influential essays, developed this concept of positive liberty (Skrabanek 1985).

[3] This is implicit in Habermas’ notion of *Verfassungspatriotismus*, Rawls’ concept of a liberal political community, and Dworkin’s ideas of “law as integrity,” and law as an expression of “political morality.” (Dworkin 1986; Habermas 1992; Rawls 1994)

[4] Seyla Benhabib (1994) tries to determine some of the basic limitations in the concept of autonomy from the feminist perspective. Feminism put focus on the bodily and emotional aspects of the self as opposed to a rationalistic and idealistic concept of autonomy (Held 1998).

[5] The relational concept of autonomy has, for example, been proposed by Seyla Benhabib (1994).

[6] It should be emphasized that the principles fundamental in informed consent emerge out of the clinical context. They should be considered as an integrated part of clinical practice and the normative implications of the physician-patient relationship in the clinical encounter. This means that autonomy, in order to understand the clinical situation, should be integrated in relation to the other principles of dignity, integrity, and vulnerability.

[7] Ricœur develops this theory in his foreword to an Edition of the French Code of Medical Deontology, *Code de déontologie médicale*, introduit et commenté par Louis René, Prefacé de Paul Ricœur, Paris 1996 and in his paper held at the First International Conference on Bioethics and Biolaw, organised by the Centre for Ethics and Law, Copenhagen 1996 (Ricoeur 2000).

REFERENCES

Ambroselli, C. (1988) *L’Éthique médicale*. Paris, PUF.

Baum, M.B. (1997) The necessary articulation between autonomy and vulnerability. *Working Papers, Research Projects, VII*. Centre for Ethics and Law, Copenhagen.

Beauchamp, T.L. and Childress, J. (1979) *Principles of Biomedical Ethics*. Oxford, Oxford University Press.

Benhabib, S. (1994) *Situating the Self.* London, Routlegde.

Callahan, D (2000) “The Vulnerability of the Human Condition”, in Peter Kemp, Jacob Rendtorff & Niels Mattsson Johansen (eds.) *Bioethics and Biolaw. Vol II. Four Ethical Principles*, Copenhagen, Rhodos International Publishers, pp. 115–23.

Charlesworth, M. (1993) *Bioethics in a Liberal Society*. Cambridge, Cambridge University Press.

Delfosse, M.L. (1993) *L'Expérimentation médicale sur l'être humain, construire l'éthique, construire les normes.* Bruxelles, De Boeck Université

Dworkin, G. (1988) *Theory and Practice of Autonomy*. Cambridge, Cambridge University Press.

Dworkin, R. (1977) *Taking Rights Seriously*. London, Duckworth.

Engelhardt, H.T., Jr. (1987) *The Foundations of Bioethics*. New York, Oxford, Second Revised Edition, 1996.

Faden and Beauchamp, T.L. (1986) *A History and Theory of Informed Consent.* Oxford, Oxford University Press.

Folshed, D. (1997) *Philosophie, éthique et droit de la medicine*. Paris , PUF.

Goodin, R. (1985) *Protecting the Vulnerable : A Reanalysis of Our Social Responsibilities*. Chicago, University of Chicago Press.

Häberle P. (1997) *Europäisches Rechtskultur*. Frankfurt am Main, Suhrkamp Verlag.

Habermas, J. (1992) *Faktizität and Geltung*. Frankfurt am Main, Suhrkamp Verlag.

Hansson, M. (1992) *Human Dignity and Animal Wellbeing.* Uppsala, Almquist & Wiksell International.

Harris, J. (1984) *The Value of Life*. London, Routlegde.

Held, V. (1998) “Rights” In Jaggar, A., Young, I. (eds.) A Companion to Feminist Philosophy, Oxford, Blackwell, pp 500–10.

Jaspers, K. (1919) *Psychologie der Weltanschauungen*, München, Piber Verlag.

Kemp, P. (2000) “Four Ethical Principles in Biolaw”, in Peter Kemp, Jacob Rendtorff & Niels Mattsson Johansen (eds.) *Bioethics and Biolaw. Vol II. Four Ethical Principles*, Copenhagen, Rhodos International Publishers.

Levinas, E. (1961) *Totalité et infini.* La Haye, Nijhof.

Nerheim, H. (1994) *Vitenskap och kommunikasjon*. Oslo, Universitetsforlaget.

Rawls, J. (1992) *Political Liberalism*. Oxford, Oxford University Press.

Reich, W. (ed.) (1978) *Encyclopedia of Bioethics*. Washington, DC., New York, Simon & Schuster.

Ricoeur, P. (1990) *Soi-même un Autre*. Paris, Èditions du Seuil.

Ricoeur, P. (2000) “Prudential Judgment, Deontological Judgment and Reflexive Judgment in Medical Ethics”, in Peter Kemp, Jacob Rendtorff & Niels Mattsson Johansen (eds.) (2000) *Bioethics and Biolaw. Vol I. Judgment of Life*, Copenhagen, Rhodos International Publishers.

Rendtorff, J.D. and Kemp, P. (2000) *Basic Ethical Principles in European Bioethics and Biolaw, Vol I. Autonomy, Dignity, Integrity and Vulnerability, Report to the European Commission of the Bio-Med-II Project Basic Ethical Principles in Bioethics and Biolaw 1995–1998*. Centre for Ethics and Law, Copenhagen, Denmark & Institut borja de bioètica, Barcelona, Spain.

Sartre, J.P. (1943) *L'Etre et le Néant*. Paris, Éditions Gallimard.

Sève, L. (1994) *Critique de la raison bioéthique*. Paris, Éditions Odile Jacob .

Skrabanek, P. (1985) *La fin de la médecine à visage humain*. Paris. Éditions du Seuil.

LAURA PALAZZANI

CHAPTER 7
PERSON AND HUMAN BEING IN BIOETHICS AND BIOLAW

INTRODUCTION

The most frequently used philosophical concept in the bioethical and bio juridical debate is the concept of person (Macklin 1983; Goodman 1988; D'Agostino 1998). Principal arguments relating to the boundaries of what is licit or illicit in the techno-scientific biomedical interventions on human life implicitly presuppose, or lead explicitly to, the question of personal status (Mahowald 1995).

The extensive use of this concept can be explained in many ways. One explanation can be found in the evocative nature of the word (at least with regard to Western culture): at a common sense level, the word "person" indicates a subject worthy of respect and protection.[1] General consensus regarding the moral and juridical significance of the word "person", might explain its wide application to bioethical and bio juridical questions, in which an ethical limit on the new possibilities of artificial intervention in human life are sought. Many bioethicists initially thought that the concept of person could be a common minimal point of agreement.

The appeal to a person's *dignity* and *rights* hides many philosophical ambiguities that demand clarification. The concept of "person" is going through a speculative crisis. What is a person? Who is a person? How should we treat a person*?* These are recurring questions in bioethics and biolaw and the replies are frequently varied, and even oppositional. While everyone may agree on considering the person as worthy (on a practical level) of being in some measure respected and safeguarded,[2] not everyone agrees on the *theoretical manner* of understanding the person and on the empirical application of the concept (that is on the conceptual definition and factual identification). In a way, the crisis of the concept might be a further reason for its diffusion; theoretical doubts make the term quite flexible and therefore adaptable to various (and even opposing) needs of postmodern society, which is characterised by complexity and pluralism (Erde 1999). Ambiguous use of the term person in bioethics has in fact led to a paradoxical *reversal of positions.* The theme of person, traditionally favoured by philosophies influenced by Christianity or metaphysics (the so called "personalism"),[3] has come to be used increasingly in the context of empiricism or functionalism.[4] The notion of person in bioethics is in fact beginning to be viewed with suspicion by those who originally formulated it. Frequently those who claim to be promoters of respect and safeguarding human life from conception to death prefer to omit or at least leave aside any reference to person, for fear of falling into dangerous ambiguities. It is clear that empiricists and functionalists

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 89–98.

make use of the concept with the intention of exploiting the intuitive emotional appeal of it, thus facilitating social acceptance of certain ideas in bioethics and biolaw. On the other hand, personalists are aware that a naïve appeal to this notion is insufficient and believe that rigorous rethinking is needed.

It is possible to discern two opposing trends in bioethics. The trend of so called "personism," in which the concept of person is central: a *separation* of the concept of person from the human being is argued (thus reducing the range of application of the concept of person with respect to human beings, and at times extending it to non-humans). According to these theories, not all human beings are persons (the human being "becomes" a person in certain conditions, or when certain external conditions are fulfilled, and a person may cease to exist before human death), but, on the other hand, some non-human beings may be considered to be persons. This trend is much diversified: there are various theories which justify placing the significant "boundaries" of personal status at different stages of human development. The usual common sense meaning of the word person changes completely in bioethics: the terms "person" and "human being" are no longer interchangeable. Then there is the trend of "personalism," which claims an intrinsic *identity* between person, human being and human life: this second trend is unitary in its theoretical and practical presuppositions, and belongs to the mainstream of western speculative tradition.

PERSONISM: SEPARATION BETWEEN PERSON AND HUMAN BEING

In the context of "personism," the human being is not a person at the moment of fertilisation, but "becomes" a person at some subsequent moment. In consequence, there are human beings who are not "yet" persons. In addition, the same theories consider that the person may end "before" the natural biological death of the human being.

A first boundary of the person has been identified, by certain authors, as the moment of the *implantation* of the embryo in the uterus. The main argument supporting this thesis is in fact a way of understanding the concept of person; in the context of a philosophical theory which emphasises *relation* (that is "intersubjective" or "cosubjective" relationship) in the definition of person (Malherbe 1985; 1988; 1990), the beginning of the person is factually identified as the phase of implantation in the maternal womb, a moment in which a very close cellular relationship is set up. From this point of view, the human embryo prior to such implantation (being devoid of any kind of relationship) would be a mere mass of cells, a being with only vital organs, belonging to the biological human species. Only after implantation (identified as a primary physiological relationship) is the related human being formed, that is the person. At the same time, this theory argues that the human being that is no longer capable of having relationship with others (because of cerebral pathologies and mental disabilities) is no longer a person. This theory excludes from personal recognition certain human beings who are incapable of relating psychologically and socially, with others (as in the case of the terminally ill in extreme existential conditions, i.e. the comatose).

This is a weak argument. If it is in fact true that relationship is an indispensable element for the existence of the person, it is also true that this does not constitute "being" in ontological terms, but it "presupposes" its existence (Sgreccia 1999).

Relationship does not, originally and structurally, constitute the subject, but on the contrary, it is in fact the subject who makes relationship possible (or even provides the condition for its possibility). There is no relationship (either physical, or even more so, psychological or social) unless the human being is capable of relating to others. Moreover, on the biological plane, even though the mother's support is indispensable and undeniable, it should also be pointed out that it is the human genome of the zygote, which has the strength to direct and guide the development in a certain direction autonomously. The relationship with the mother is one of the many "extrinsic" relationships (perhaps one of the most important, but not the only nor the decisive one) which guarantee the conditions for development.

Some authors state that the person begins not before *the fourteenth day* after conception, since only at that moment is the *individual* formed (Ford 1988). According to this theory the monozygotic twins phenomenon is proof that the zygote cannot be an ontological human individual: one individual (in the classical definition, individuality means "indivisibility") cannot become two individuals. The totipotentiality of the embryo-cells deny, at a biological level, the (conceptual) quality of individuality (at least until the end of the period of the possible separation into twins).

However, this phenomenon is a real exception; it logically means that the zygote is determined to develop as a unique human individual. Moreover, very recent studies support the hypothesis that twinning is not a separation but "duplication":

> It seems very reasonable to state that there is one first human being, from whom a second human being originates, beginning a new life cycle. On the contrary, it doesn't appear correct to affirm that one undetermined system becomes two determined systems (Serra and Colombo 1998, 128).

Another boundary of personal status is identified by some (Singer 1993; Singer, et al. 1993) as the moment of *formation of the central nervous system,* when pleasure and pain can be felt. From a utilitarian view point, according to which the unique criterion in ethics and law must be the calculation of the costs/benefits (that is maximisation of benefits and minimisation of costs), and the *possibility of possessing interests* (to reach benefits and avoid costs) is considered to be the constituent element for the attribution of personal status to a subject. The beginning of a person is identified (as a minimal condition) with the beginning of sensitivity understood as the perceptive capacity (instantaneously) to desire to maximise pleasure and avoid, or minimise, pain. From this point of view, the morally and juridically relevant characteristic is the possession of sensitivity. This means that any specific distinction (known as "specist" by upholders of this point of view) between humans and animals cannot be affirmed, the result being the extension of the principle of equality biocentrally (or better, pathocentrally) beyond the human species, to include non-human animals.[5] The same theory, at a maximal level, recognises as a person (in a stronger sense) only a being (human or not human) who is in a condition (existentially) to maximise pleasure and happiness and minimise pain and unhappiness (for him/herself and for others). Human beings who suffer or have the probability of suffering (and make others suffer or have the probability to do so) cannot be considered persons (in this sense). Anyway, according to utilitarian theory, a suffering (or even non suffering) being (human or non human) may be killed by "painless" methods or techniques.

But the presence of the sensitive function, or of the conditions for its manifestation, presupposes a subject who perceives (experience presupposes a subject, it does not constitute it); it is therefore the existence of the subject which makes the exercise of certain functions possible, not the exercise of the functions which constitute the existence of the subject. Moreover, the utilitarian concept of subjectivity presupposes that the unique motive for action is the conscious pursuit of pleasure and avoidance of pain, while what in fact characterises human beings,and what differentiates them from animals is their capacity to act out of duty. Furthermore, the reduction of minimal recognition of a person to the presence in a subject of pleasurable sensations leads, paradoxically, to the impossibility of recognising the person, since it is not possible to be certain of the existence in another (whether human or at least animal) of an experience of pleasure or pain (experience which is structurally subjective), and thus which cannot be quantified or calculated: anyway, the perception of pleasure and pain of humans is different from that of animals; humans can give a sense to pleasure and pain (this is structurally impossible for animals, that they only react instinctively). Moreover, eliminating pain is not the same as eliminating life (the two actions have different moral and legal meanings) and the indirect effects on others (with regard to suffering) can't be seen as the direct cause of a certain action, such as suppression of a human being.

The beginning of the person is identified by other authors as the moment of *formation of the cerebral cortex*, considered essential for the exercise of *rationality.* This rationalistic view of the person, which considers reason to be his/her constituent element, holds that in a minimal sense, ascertaining the presence of neurophysiological conditions which permit organic development, is indispensable. This is the notion upheld by the theorists who propose a parallelism between "brain death" and "brain life"; in other words, those who identify the birth of the human subject with the establishment of cortical activity, in parallel to the identification of the death of the subject with the cessation of the cerebral function (Fletcher 1974; Goldenring 1985; Jones 1989). It is also maintained by the theorists of "emergentism" (Mori 1990; Rich 1997) whose materialistic theory holds that new and transcendent properties (such as the mind) may "emerge" from the combination of several parts (in this case the cerebral cortex).[6]

However, there can be no mirror-correspondence between life and death, either conceptually or empirically. On the conceptual plane, death is the negation of life (it could only be said that between life and death an intuitive verbal association by opposition is established). On the empirical plane, cerebral death is the immediate, permanent, irreversible and pathological cessation of the unity of the organism. While the beginning of cerebral activity in embryogenesis is characterised by the continuous and progressive increase (generally non pathological) of a highly intense neurological relationship between cells, tissues and organs. It should be added that emergentism does not explain how the conscience "emerges" from matter. From a materialistic point of view, only quantitative differences, or differences of complexity can exist, but there is no explanation of how a different level of organisation of matter could constitute a qualitative leap, a change of nature, a novelty, irreducible to matter, and transcendent in respect to it.

Another theory insists on the indispensability of *reason*, understood as an *effective exercise*, for the definition of the person. It is the neocontractual theory, according to which a being (human or non human, living or non living) is a person only when he/she is a "moral agent," who is able to make a contract with others, that is, who is able to make an agreement on ethical conceptions of what is good or evil (building, by contract, a "moral community"). Every member belonging to a particular moral community is a "moral stranger" with regards to the members of other moral communities. This theory identifies the person in the post-natal stage of life (excluding the personal status of the embryo, but also of the fetus and infants; indeed, possibly even of those who can be defined as minors) at the moment of the *acquisition of self-consciousness* (Tooley 1983), or at the moment of the *manifestation of intellectual activity, freedom, moral sense and self-determination* (Engelhardt 1996) (thus the ability to understand, will and evaluate). For the same reasons, this theory considers human beings incapable of rational thought and decision making as non-persons (or post-persons).

The functionalist theory assumes that the person possesses and is able to exercise a number of functions. However, the performance of a function is not an abstract hypostatis, but is inseparable from the *ontological subject* who is the condition of its existence. Moreover, if the coincidence between person and function (self-conscious, rational and in possession of will) were true, the sleeping or inebriated human being (or any human individual who only shows the function required for the attribution of the status of a person intermittently or has been temporarily suspended), would not be a person (Minogue, et al. 1997).

PERSONALISM, BIOETHICS AND BIOLAW: IDENTIFICATION OF PERSON WITH HUMAN BEING

From this brief critical review of the personist theories in bioethics and biolaw, it emerges that the notion of person, separated from its origins, is today taking on new roles which endanger its own specific, intuitive and original values. The concept of person originally developed in philosophy to characterise the human being and is being used today "against" humankind itself., to the point where, after the phenomena of slavery, colonialism, racism and sexism, we now find ourselves faced with a new form of human discrimination, more subtle and hidden, because it touches "borderline cases": discrimination against zygotes, embryos, fetuses, and even against infants, children, the handicapped, brain-damaged, elderly, comatose, and terminally ill patients. After the hard-won achievement of a universally accepted "secular faith" in the dignity of man and in human rights (outlawing all racial, sexual, economic, religious and political discriminations), *as a result of an ambiguous use of the concept of person* in bioethics, new discriminations are beginning to emerge, and specifically *discrimination in terms of the degree of physical, psychological and social development of the human being.*

Does it any longer then make sense to use the concept of person in bioethics and biolaw (Beauchamp 1999; Gordin 1999)? In effect, the recognition of the dignity and rights of the human being may, in principle, rule out the discussion of the concept of person. The concept of person is not indispensable for morality and law; concrete proof of this can be seen in the fact that for centuries in the Western tradition, in ancient Greece and pre-Christian Rome, there was reference to human dignity without the elaboration of any concept of person. In oriental thought, too, the moral and juridical value of the human being has been recognised on the theoretical plane even though the philosophical category of person was unknown, or at least not formalised in theory (Carrithers, Collins and Lukes 1985). The actual doctrine of human rights considers the human being as such, without introducing the concept of person.

But, even though we may undoubtedly recognise the theoretical possibility of avoiding the use of the concept, we should not forget that the notion of person was actually devised in Western philosophy for the precise purpose of characterising the human being and of justifying humanity's centrality. This is a concept which forms part of our cultural tradition, and if used in its original meaning (often involuntarily or intentionally misunderstood and modified), it can be helpful in the discussion of the *objective claims to respect and safeguard the human being*. To recognise the expression of a personal life at every stage of the development of the biological life of the human organism (from the initial moment of conception to the final instant), is not a useless philosophical effort. To say that "the human embryo is a person" or "the comatose is a person" is not a mere tautology. To endow the human being with the status of person means to say *something more* than the mere empirical acknowledgement of the biological humanity of that being. The identification of the human being as a person (where the concept of person is defined in preliminary terms on the theoretical plane), at the philosophical and anthropological level, specifies the characteristics and the constituent property of the human being, and in the final instance explains the basis of the person's values and rights.

Thus, what should be eliminated is not so much the use of the term person itself, but its vague, uncertain and unclear use. In order to combat this ambiguity, it is indispensable that the speculative effort of personalism should be directed at the *re-definition* of the subject within the context of a philosophy of the person and of the human, which will be capable of providing justification for the *identity between human being and person.*

It should first be noted that *the definition of person was originally devised to characterise the real human being.* This makes it possible to introduce an epistemological point: the devising of a concept cannot be divorced from the reality to which it refers. It is the concept which is to be measured against reality, not, on the contrary, reality which must conform to the concept (or which is excluded if it proves to be inadequate for it).

The departure point for philosophical definition always remains reality, but reality examined from a certain point of view; not from the point of view of empirical argument (or rather not exclusively from that point of view), but instead *from the philosophical standpoint.* Philosophical definition seeks the meaning, the essential specific character of the real human being, as a radical ontological condition. The philosophical definition which is best suited to making it possible to re-think the concept of person in the overall and integral sense, identifying it empirically with the real human being, is the definition, originally formulated by

Boethius[7] ("*rationalis naturae individua substantia*"[8]), reformulated in a more complete form by Thomas Aquinas ("*individuo subsistens in rationali natura*"[9]), the person is the individual substance of rational nature.[10]

A first element in the definition, which must be clarified, is the recovery of the concept of *substance*. Substance is meant, according to Aristotle, in general, the specific individuality of something; individual substance is the distinct subject which exists in itself, not inherent to anything else, or which belongs only to itself.[11] The existence of the individual substance is demonstrated by pointing out the contradiction into which anyone who denies it falls: whoever affirms that certain qualities and certain determinations are "of" something or "of" someone, implicitly indicates a determined substance. Experience shows us that multiple characteristics refer to one single entity, and that bodies change and are transformed, yet remain the same. By applying the concept of individual substance, understood in this way, to the human being in particular, it becomes clear that the functions which he/she exercises and the acts which he/she undertakes do not exist in themselves, but exist only as functions and activities "of" a substantial human individual, who is their singular and permanent reference-point, their real ontological condition. It is substance understood in this way which makes it possible to explain the *unity* (in space) and the *permanence* (in time) of the identity of the human being. Man is not reducible to a "bundle of phenomena"; understood in this way man would dissolve in the multiplicity of characteristics and would resolve into the sequence of acts. In other words, man would not be a "being," but his own "doing" (Lucas 1993, 243).

The definition of person further characterises human nature in relation to *rational nature*. The expression "nature" in Aristotelian terms means, what the person "is" by virtue of birth (or, one might say also, by virtue of having been conceived); by the mere fact of existing, of living. The adjective "rational" does not merely indicate intelligence and rationality (as cognitive capacity for comprehension or logical calculation), but in a broad sense it indicates reason and thought, word, language, communication, liberty and intention.

On the basis of substantialist theory (of ontological personalism), we can affirm that the human being "is" a person by virtue of his rational nature, not that he "becomes" a person by virtue of the effective exercise of certain functions (such as relational capacity, sensibility and rationality). The personal being belongs to the ontological order: the possession of a substantial personal status cannot be acquired or diminished gradually, but is a radical condition (one is not more or less a person, a pre-person or a post-person, but either a person or not a person). The absence (understood as non-actuation or privation) of properties or functions does not deny the existence of the ontological referent, which remains such by nature, since ontologically speaking it pre-exists his/her own qualities.

The functions are "of" a person (in that they inhere to his substantial nature), they are not "the" person. It is not from the possession of certain properties or the manifestation of certain functions that the presence of the person may be deduced, but on the contrary, the person is the real condition for the possibility of the existence and the performance of certain functions. The presence of a substantial principle makes it possible to recognise the actual status of the person in the human being even in conditions of "potentiality" or "privation." The non-actuation, momentary or permanent, of certain functions, due to the incompleteness of development or to the presence of factors, external or internal, impedes or hinders that manifestation.

It follows that the zygote, the embryo, and the fetus (and also the newly born or the minor) are “already” persons. Although all the properties are not yet manifest in practice, or to the maximum degree, the conditions for the uninterrupted dynamic gradual and co-ordinated process are nevertheless present from the moment of conception. Similarly, the moribund, the handicapped, people in comas, are “still” persons, in that although the subjects are deprived of certain properties, the intrinsic possibility for their nature still exists. The real qualitative leap is at the moment of conception (ending with death): as soon as the two gametes interact, a new organic system (which is more than the sum of the parts) begins working as a new unit, intrinsically determined to reach his/her final form autonomously, in a process which is characterised by co-ordination and continuity.

Philosophical reflection on these biological data shows that there is no dissociation between the phenomenological and ontological aspects of the person. It is evident that confusion exists between ontology and phenomenology; the embryo or the dying person are not manifested in the same dimension, form, and consciousness as the adult human being,, but the incomplete manifestation does not modify the ontological status. The quantitative imperceptibility of the embryo, like the existential fading condition of the terminally ill, does not render them, ontologically speaking, any less persons.

This is the only way of understanding philosophically the concept of person which could relate to the doctrine of human rights, which is universally (almost on the level of principles) agreed upon and recognised. If there is no ontological difference between the stages of development, we must recognise that every human being (even at the beginning or at the ending of life) has the dignity and rights of a human person. We must recognise our duty to respect all human beings and we must recognise the fundamental rights to life and integrity of every human being at every stage of physical, psychological and social development. In this sense, bioethics and biolaw are called to defend the dignity of human life, prohibiting every artificial intervention that is not carried out for the overall wellbeing of the human being (D’Agostino 1998). Human life must not be exploitable for scientific or experimental purposes: human beings must always be recognised as an end, and never just a means. This is the only philosophical basis that justifies, in relation to scientific and technological progress, the need to defend and safeguard human life from conception to the final moment.

NOTES

1. The close relationship between the concept of person and the consideration of ethical and juridical relevance is to be found in the original philosophical meaning of the term (according to which, as Thomas Aquinas pointed out, persons were men endowed with dignity), in the traditional use of juridical language (in Roman times, the person already referred to humans as individuals possessing rights), in addition to the strong influence of Kantian thought (which recognized every man as a person, that is always an end and not just a means).

[2] However, it should not, be forgotten that respect and safeguarding are attributed to the person unanimously in qualitative terms, but not in quantitative ones: there are differing levels of respect and safeguards recognised.

[3] Personalism is a philosophy which places the concept of person at the centre of philosophical reflection, in the context of varying speculative presuppositions. There are various versions of personalism (the community-based personalism of E. Mounier and L. Stefanini; the spiritualist personalism of C. Renouvier, J. Lacroix and M. Blondel; the existential phenomenological personalism of M. Nédoncelle, N.A. Berdjaev, G. Marcel and M. Merleau-Ponty; the dialogical personalism of M.Buber; the hermeneutic-symbolic personalism of P. Ricoeur; the Thomist ontological personalism of J.Maritain, who returns (though with some variations) to the origins of the concept in the Thomist formulation.

[4] Within the context of this consideration, an exception is the concept of person as relation, which concerns a special orientation of philosophical personalism, or dialogical and relational personalism, as opposed to ontological personalism.

[5] If the utilitarian concept of the person may seem at first fairly inconclusive, since it is declared to be in defense of all sentient beings, a more careful examination will reveal the strong discriminatory loading towards humans. Above all, this concept excludes from protection non-sentient humans (this is the case for both embryos and the comatose, devoid of perceptivity), but at the same time it only protects sentient beings weakly, guaranteeing them only the right not to suffer uselessly (thus permitting interventions that may be suppressive but painless, or interventions on the subject who feel more pain than pleasure).

[6] The theory of "retarded animation" will not be discussed in this essay since it implies references to the theological debate (Donceel 1970; Diamond 1975). It is enough to mention that while it is true that St. Thomas upheld this theory, it is also true that this should be seen in the historical context of the period when the author wrote (with the inevitable conditioning of the biological and theological knowledge of the time. For instance the morphological notions distinguished between the active power of the seed and the passive power of the woman; theology was forced to come to terms with the theories of traducianism which held that the soul is transferred from father to son without divine intervention). If Thomas had had the scientific knowledge of today available to him (which bears witness in genetic terms to the formation of the individual patrimony by means of both the father and the mother, in addition to the continuity and gradual nature of the development of the embryo), on the basis of the substantialist philosophical assumptions, he would have upheld immediate animation (Heaney 1992).

[7] It should be remembered that the need to recover the traditional definition of person within the context of bioethical questions was maintained and justified by E. Sgreccia (1989a; 1989b; 1990)

[8] S. Boethius, *Contra Eutychen et Nestorium*, III, 1–6; *De duabus naturis et una persona Christi*, III, in Migne, PL 64 col. 1345.

[9] For the classic definition see TOMMASO D'AQUINO, *Summa Theologiae,* I, q.29, a.3: "persona (...) significat id quod est *perfectissimum* in tota natura, scilicet *subsistens* in rationali natura"; q.29, a.3, ad 2 (Seidl 1987).

[10] It should not come as a surprise that in the context of the explanation and justification of the definition, reference is not only made to the authors who originally formulated (in particular St. Thomas), but also to Aristotle. In fact the latter, although not having developed the notion, had already discussed (eight centuries earlier) the philosophical categories which constitute its principal elements.

[11] For the exposition of the concept of substance in Aristotle see Aristotele, *Metaphisica* Z, 7, 1032b 1–6. For an analysis of the concept of substance in Aristotle, and the lines of the critique of his argument, see E. Berti (1989).

REFERENCES

Beauchamp, T.L. (1999) The failure of theories of personhood, *Kennedy Institute of Ethics Journal* 9, 309–24.

Berti, E. (1989) Il concetto di "sostanza prima" nel libro Z della Metafisica, *Rivista di Filosofia* 80, 3–23.

Carrithers, M., Collins, S. and Lukes, S. (eds.) (1985) *The Category of the Person. Anthropology, Philosophy, History*, Cambridge University Press, Cambridge.

D'Agostino, F. (1998) *Bioetica nella prospettiva della filosofia del diritto*, Giappichelli, Torino.

Diamond, J.J. (1975) Abortion, animation and biological hominazation, *Theological Studies* 36, 305–24.

Donceel, J.F. (1970) Immediate animation and delayed hominization, *Theological Studies* 31, 76–105.

Engelhardt, H.T., Jr. (1996) *Foundations of Bioethics*, Oxford University Press, New York.

Erde, E. (1999) Paradigms and personhood: A deepening of the dilemmas in ethics and medical ethics, *Theoretical Medicine and Bioethics* 20, 141.

Fletcher, J. (1974) Four indicator's of humanhood: The enquiry matures, *Hastings Center Report* 4, 1–4.

Ford, N. (1988) *When Did I Begin? Conception of the Human Individual in History, Philosophy, and Science*, Cambridge University Press, Cambridge.

Goldenring, J.M. (1985) The brain-life theory: Towards a consistent definition of humanness. *Journal of Medical Ethics* 11, 198–204.

Goodman, M.F. (ed.) (1988) *What Is a Person?* Humana Press, Clifton, NJ.

Gordin, B. (1999) The troublesome concept of the person, *Theoretical Medicine and Bioethics* 29, 347.

Heaney, S.J. (1992) Aquinas and the presence of the human rational soul in the early embryo. *Abortion: A New Generation of Catholic Responses*, The Pope John Center, Braintree, MA, 43–71

Jones, D.G. (1989) Brain birth and personal identity, *Journal of Medical Ethics* 15, 173–8.

Lucas, R. (1993) L'essere sostanziale dell'uomo: La persona. *L'uoma spirito incarnato, Compendio di filofia dell'uomo* Paoline, Milano p. 243

Macklin, R. (1983) Personhood in the bioethics literature. *Milbank Memorial Fund Quarterly Health and Science*, 61, 37.

Mahowald, M.B. (1995) Person, in Reich, W.T. (ed.), *Encyclopedia of Bioethics,* 2nd Ed. Macmillan, New York, 1934.

Malherbe, J.F. (1985) Groupe international d'études bioéthiques de la Fédération internationale des Universités catholiques.

_____. (1988) Le statut personnel de l'embryon. Essais philosophique, in A.A.VV. (ed.), *Débuts biologiques de la vie humaine. Des chercheur chrétiens s'interrogent.* l'Hartmattan-Ciaco, Paris-Louvaine-La-Nueve, 103–19.

_____. (1990) *Pour une éthique de la médicine*, Ciaco, Louvain-La-Nueve.

Minogue, B., Brendan, P. Palmer-Fernandez, G. and Reagan, J.E. (1997) *Reading Engelhardt: Essays on the Thought of H. Tristram Engelhardt, Jr.*, Kluwer Academic Publishers, Boston.

Mori, M. (1990) Il feto ha diritto alla vita? in L. Lombardi Vallauri (ed.), *Il meritevole di tutela*, Giuffrè, Milano, 735–55.

Rich, B.A. (1997) Postmodern personhood: A matter of consciousness, *Bioethics* 11, 206.

Seidl, H. (1987) The concept of the person in Thomas Aquinas, *The Thomist* 51, 437–8.

Serra, A. and Colombo, R. (1998) Identity and status of the human embryo: The contribution of biology, in De Dios Vial Correa, J. & Sgreccia, E. (eds.), *Identity and Statute of the Human Embryo*. Libreria Editrice Vaticana, Città del Vaticano.

Sgreccia, E. (1999) *Manuale di bioetica I. Fondamenti ed etica biomedical*, Vita e Pensiero, Milano.

Singer, P. (1993) *Practical Ethics*, Cambridge University Press, Cambridge.

Singer, P., Feinberg, J., Baum Levenbook, B. (1993) Abortion, in T. Regan (ed.), *Matters of Life and Death. New Introductory Essays in Moral Philosophy*, McGraw Hill, New York, 195–234.

Tooley, M. (1983) *Abortion and Infanticide*, Clarendon Press, Oxford.

JUAN RAMÓN DE PÁRAMO ARGÜELLES

CHAPTER 8
WELFARE RIGHTS AND HEALTH CARE

There is some consensus regarding the crisis of the Welfare State in Spain, especially in regards to the external causes that demonstrate the existence of such a crisis: economic stagnation accompanied by inflation (stagflation), unemployment problems, the financial crisis of the State, which results in a gap between revenues and the resources needed to fund public spending. All this has contributed to a policy of deliberate cuts in the social services budget, and more importantly, to a general loss of confidence in the Welfare State system. The effectiveness of government action and its sphere of operation are being questioned. It is true that many solutions, based on different assumptions and arguments have been proposed, but there is not the same consensus regarding treatment as there is regarding diagnosis. The unlimited demand for welfare protection and the rising cost of resources make public supply of welfare rights a problem that can no longer be ignored. As a result, various solutions to this dilemma have been offered that stress different approaches. The *liberal* solution (capitalisation of pensions through their own self-financing) contradicts the *collective* solution (universal transfer of income to a common account), while the Social Democrat or *neo-corporate* solution tries to reach an agreement on incomes and pensions through a previously negotiated contract. However, such attempts at resolving the dilemma simply make the already questionable level of effectiveness of government action even more evident.[2]

Despite the difficulties in financing the growing deficits generated by public spending on welfare protection, and the demands to limit welfare rights – the more radical critics are calling for drastic cuts or even for its elimination – the liberal solution regarding healthcare spending does not appear to support a reduction in spending. In Great Britain, following Prime Minister Thatcher's reforms, healthcare spending grew at a dizzying pace. In the United States, healthcare spending – which is almost entirely private – is, per inhabitant, four times greater than in Spain. This, however still does not prevent 16.5% of the population from lacking medical insurance and another 56% from having very limited coverage. The case of Catalonia, where the *Generalitat* has made extensive use of private management, is especially significant.

In Spain, data reflects a serious deficiency in welfare programs. In addition to being one of the EU and OECD countries with the worst distribution of wealth and income, Spain is also one of the EU countries with the highest infant mortality rates and one of the lowest growth rates of life expectancy. In the EU, Spain is one of the countries that spend the least amount of public funds on welfare issues. In total, welfare spending in Spain is only 20.6% of the GDP (the average in the EU is 27%), a percentage that has been falling since 1993, when it stood at 24%. Economic

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 99–109.

growth and falling unemployment rates have not covered these social deficits but instead have only reduced the general budgetary deficit. Spanish healthcare spending makes up 5.8% of the GDP, much less than the average of 7.4% in the EU. As a result of the enormous power of the pharmaceutical industry, Spain is one of the countries that spend the greatest percentage of public healthcare funds on medicine (20%). If we take away this 20%, we observe that non-pharmaceutical healthcare spending is only 4.6% of GDP, the lowest percentage in the EU, along with Greece. The consequences of such nearsightedness become apparent in the long waiting lists for major surgery, and the short amount of time allotted to primary care visits. Within healthcare, the area that enjoys the fewest resources is public health; Spain is one of the countries with the highest percentage of HIV/AIDS cases, drug addiction, tuberculosis, venereal diseases, *legionnaire's disease* and other infectious illnesses. The lack of financial resources is frequently accompanied by the State's passive attitude towards its responsibilities for regulating and sanctioning.

In this brief chapter, I will discuss the concept of *welfare rights*, making special reference to the right to health care, the contradictory nature of which highlights the doubts and disagreements over the limits on welfare spending, and particularly, on public healthcare. In other words, I will attempt to demonstrate how a theoretical question can have important practical consequences. However, to put these rights into effect, a considerable rise in welfare spending is required to reach the EU average, which requires an increase in State revenues, whether by raising taxes or incurring a larger deficit. It is impossible to suggest reaching a zero deficit, lower taxes, and at the same time resolve the enormous deficit in welfare programs.

I

Health protection is one of the most important features shaping Spain as a Welfare State. When the State produces legal structures to defend health, such measures become an invaluable instrument to better understand state organisation as a whole, as well as the current legal system.

Until the middle of the last Century, the Spanish State considered health matters to be of no more importance than any other subject. However the important development of the demand for medical assistance as a right became increasingly widespread with the creation of social security systems. The latter is understood today as a method designed especially to combat need, that is, a specific way of providing for that need. One must remember that welfare rights arose precisely as a collective insurance against the risk of misfortune since these *social* problems did not allow for *individual* solutions.[3] For this reason, historically, a collective solution in the form of obligatory insurance arose against the risks of misfortune – such as illness – thereby solving the problem through the creation of those *public goods* which are the social rights guaranteed through welfare policies. The so-called Welfare State is characterized by its explicit obligation to provide assistance and support to citizens who suffer from specific needs and risks. But such obligations are not derived from extra interventions in times of emergency – a charity of sorts to compensate for failure – but instead from institutional interventions based upon the recognition of individual indigence as a structural feature of modern society. The Liberal State of the 19th century could only guarantee a limited form of freedom,

freedom as non-interference, “freedom to sleep under bridges,” as Anatole France sneered. However, freedom is not only threatened by despotism but also by hunger, misery, ignorance, and dependence. If civil and political rights were thought of as restraints on the arbitrary whims of political powers, calling for inhibition or self-control from the State, then welfare rights require positive contributions from the Welfare State in the sense that they can only be practised by means of social action. They are rights which require the establishment of an administrative institution to respond to the demands of individuals in the form of public service.

Our legal structure politically defines Spain as a social and democratic State, tied not only to traditional civil and political rights, but also to welfare rights. In this sense, social security not only forms part of the institutional structure of the State, but its benefits also constitute a substantial part of welfare rights.

Unfortunately, the Spanish Constitution‘s classification of welfare rights as *subjective rights*, which by design were intended to guarantee classic civil and political freedoms, gives rise to numerous difficulties.[4] And this is where several of the problems or paradoxes of the Welfare State begin. Holmes and Sunstein say that although the costliness of rights should be a truism, it sounds instead like a paradox, and an offence to polite manners, or perhaps even a threat to the preservation of rights. It is a widespread but obviously mistaken premise that our most fundamental rights are essentially without cost (Holmes and Sunstein 1999).The concept of *welfare rights* is constructed as analogous to *individual rights*, although their historical origins are as different as their inherent nature and limits. Individual rights (e.g. freedom of speech) originated historically through the regulation of a protected environment limiting the intervention of political power, and in the establishment of areas of immunity or limits on State intervention. Welfare rights, on the other hand, were proclaimed to call for the direct intervention of the State, because the State represents the public institution responsible for implementing those rights; welfare rights establish where the State can and must intervene. While classic public freedoms impose negative obligations on the State – protected spheres of individual autonomy that cannot be invaded – welfare rights demand positive contributions from the State, which may be held liable in case of omission. The differences between the two types of rights affect their level of protection, nature, recognition, and how they are put into practice. The methods used to guarantee one’s freedom of speech cannot be the same as those used to universally guarantee the right to health care. The latter requires a meticulous and extensive process of proposing, adopting, and executing public policies involving costly resources and prioritising different alternatives. The diachronic variability of social rights – changes perceptible over the passage of time – their synchronic differences between different societies, and their structural dependence, arising from the social position of those who possess them, contradict the universal and egalitarian demands of individual rights, even while recognising their particular historic and cultural origin. Furthermore, while the exercise of individual rights is independent of other subjects, the exercise of welfare rights is interdependent, that is, their levels of recognition depend upon each other in such a way that any change in the welfare of a subject triggers correlative changes in other subjects.[5]

The problem lies in that the generic term “rights” encompasses both individual rights and welfare rights, which creates a perverse result: “...with respect to welfare rights, there is the hope for the same type of recognition that is only possible with individual rights. This process of the individualisation of welfare rights is not only erroneous but also paradoxical, given the many irreconcilable contradictions that it gives rise to (Gil Calvo 1994, 22).”[6]

This transfer of distinct properties of individual rights to welfare rights caused by such identification produces three perverse effects. First, with the demand of *everything right now* – the exercise of individual rights cannot be delayed due to economic reasons – comes a phenomenon of *unlimited expansion*, which makes demand grow more rapidly than resources. Moreover, all public policy regarding welfare generates a series of secondary effects, such as the subjective perception of unfair treatment and the justified defence of legitimate rights that cause an unlimited growth in demands. If we add to this the corporate interests of the agents in charge of providing social services – result of a *stigmatisation* process, which will be analysed later in this paper – we find ourselves with an unstoppable process that is difficult to control.

However, the expansion of welfare rights – manifested by the rising percentage of beneficiaries in the population and a relaxation in the requirements necessary to receive benefits – has gone through three phases.[7] The first one is the *workers' compensation* phase, which covered the period between the Bismarck laws and the First World War. During this time various types of insurance against very specific risks – illness, accident, disability – were introduced and financed through a tripartite model: worker-beneficiary quotas, employer quotas, and State contributions. A second phase of *social security* corresponded to the period between the World Wars and was characterised by an increase in the percentage of the population covered due to an expansion in covered risks. The third phase of *social security* begins with the aftermath of the Second World War, with a policy of assistance clearly oriented towards subjectively universalising coverage, and practically adopting welfare rights as constitutional rights.[8] On the other hand, universalising welfare rights has shown itself to be compatible with the principle of strategic diversification that gives rise to specific welfare rights for different groups according to profession, age, or income. It is obvious that the universality of these rights refers to their possession and not their exercise. The universality of the right of health care does not require one to suffer the relevant need, but instead guarantees that if one is ever suffering, adequate assistance will be received.

Professor Contreras has pointed out an important connotation evoked in the process of universalising welfare rights: the problem of *stigma.* Contreras signals that the term *stigma* originally served to designate the physical mark engraved on the skin of a slave or criminal. These marks later came to signify the attributes relative to a person's reputation or category. To stigmatise a person is equivalent to describing him in culturally offensive or unacceptable terms. In the realm of welfare rights, it is debated whether or not it is inevitable for beneficiaries of welfare services to perceive themselves under the humiliating category of “parasite” or “failure”. The problem stems from the fact that the *ethos* of mutual reallocation at the root of welfare rights still has not managed to displace the bilateral logic of the economy, based upon the principle of balanced exchanges, and on the idea that "no one gives something for nothing." In market relationships, where nothing is given for free, this stigma does not exist. Instead, what occurs is a simple adjustment or negotiation of individual interests. By contrast, in the case of welfare contributions, a transfer of resources – from the contributors to the needy – takes place, a displacement of an ambiguous nature, even for the beneficiaries themselves. As citizens, we continue to not to take welfare rights seriously. This generates a systematic distrust of the beneficiary, who is often accused of being a fraud or a parasite. This mistrust also extends to the provider of welfare services. The weight of the presumption of wastefulness and incompetence fall squarely on the managers of public services. In the United States, welfare services have repeatedly been condemned and the terms, *bureaucrat* and *bureaucratic,* have often been used as insults.

The second significant undesired effect of equating personal and welfare rights is that of *inflationary devaluation*. This is a process by which any addition to the level of protection of a welfare right inexorably contributes to lowering the degree of satisfaction associated with the previous level. This problem, which is quite evident with regards to education rights, occurs very frequently in the area of welfare rights, as is the case of the right to health care. When defending a system of public health, one must recognise that medical assistance in the case of illness must be a universally egalitarian right. This is the case under public systems of social security that demand obligatory health insurance. Since a greater public benefit (rather than private benefit) is derived from such protection – health is a public good – it must be paid by the public and should not be abused to receive private benefits. [9]

The objective of public health care is to try to insure the entire population against the *risk of misfortune*. As this carries a high cost, distributing this cost among the entire population can help to minimise it. Therefore, obligatory social insurance becomes a public good that only the State can guarantee. Welfare rights protect against the risk of certain deficiencies and compensate for the possibility of failure due to misfortune, but they must never be a guarantee of good fortune that may increase one's probability of success. It is one thing to compensate for unfortunate circumstances and calamities, another thing to gain an advantage and actually increase the probabilities of success. Indeed, it is true that the distinction is sometimes difficult to establish, especially in healthcare. There are cases in which the distinction is clear, for example, the difference between treatment given for a brain tumour and minor plastic surgery for aesthetic improvement. However, the concept of *quality of life* is relative, and not everyone would agree on eliminating plastic surgery from the sphere of free public assistance. At times, such interventions do not yield competitive advantages but instead merely compensate for situations of inequality due to misfortune.

If such a distinction is not established, one can easily fall into the third perverse effect, the so-called "Matthew Effect",[10] where ending the suffering caused by misfortune is confused with seeking out a comparative advantage. Here, the undesirable situation would be that those in need are unaware of how to take advantage of their welfare rights, while others, who do not suffer such need, know how to reap the benefits of welfare rights as if they were comparative advantages.

This can exhaust those welfare rights that are public goods. It is essential to remember that the Welfare State was conceived to address the social problems of indigence, illiteracy, and illness by generating the corresponding public services. But given the existence of public goods, the most rational individualist strategy would be to enjoy the benefits to the maximum whilst avoiding in any way contributing to their cost.[11] This is the tragedy of communal goods: they are first over-used, then become saturated, until finally they lose all value and become depleted. This affects public property as much as it does public services – hospitals and universities – as well as natural ecosystems. The rational individualist strategy privately exploits, in the name of individual rights, public goods that legitimately exist only to satisfy welfare rights. This contributes, to a saturation of the system due to the demand for welfare protection.

II

Unlike the institutional structure that the Liberal State constructed to guarantee individual rights, the Welfare State has not been able to offer the same protective mechanism with respect to welfare rights. Their different nature, content, and limitations in exercising them, have not made such an arrangement possible, in spite of the fact that they have hastily been regarded as similar. Given the heterogeneity of interests that welfare rights protect, situations of a completely different nature prevail when these rights are claimed as a reflection of different subjective legal situations advantageous to their holders. Moreover, as we have seen, they require a certain structure and organisation in the economic and social fields in order to be carried out, which makes it necessary for them to be graded and to have a relative nature. Their intrinsic dynamism hardly fits in the scheme of general or abstract legal norms. Yet that does not imply condemning welfare rights as precarious or considering them to be an undeserved and unsustainable luxury because, among other considerations, it must be observed that no right is self-executing: all rights, along with political freedoms, presume large efforts on behalf of the State, through institutional programs or other mechanisms. The proactive or participatory character of welfare rights can also be an attribute of some of the so-called political rights, in the same way that an institutional and normative framework of a coercive nature is necessary for the economy to exist.

A brief analysis of our legal system leads us to conclude that there is a lack of correlation between the organisational structures of the constitutional system and the set of principles, values, and rights codified in the current constitutional texts. Welfare rights suffer from this organisational weakness.[12] The significant economic character of welfare rights once again gives rise to questions regarding the political and constitutional limitations of the Spanish Constitution‘s “economic model” and of the free market. It has also been said that welfare rights are inherently unjustifiable, as they are not concrete, because they are considered only as a starting point for later regulatory developments. Regardless of these limitations, one must remember that according to the Constitution, welfare rights constitute the essential nucleus of the social and democratic State. Their insertion in the Spanish Constitution provides them with a normative character and not merely a declarative or rhetorical one, even though they are included under the first section’s third chapter, "Ruling Principles of Social and Economic Policy" and not under the second chapter, "Rights and Freedoms." Constitutionally recognised welfare rights are rules to be obligatorily complied with and not just future expectations or idealistic promises of good intentions.

The ties between public authorities and the legal system oblige them to recognise, respect, and protect welfare rights, as well as to ensure that they are fulfilled. However, the constitutional legal system allows the legislator to determine the extent and limits of the demands of the material requirements of the rights guaranteed by the Welfare State. Such limitations will depend upon the political parties in power and on the social and economic climate of the moment. In a parliamentary democracy, this power corresponds to the various majorities that can be grouped together to support projects that either increase or decrease welfare rights.

What are the limits on exercising or ignoring welfare rights? Can any citizen demand and receive the full extent of his rights? Could frustration of his expectations constitute a Constitutional violation? In that case, is recourse taken to ordinary tribunals or does the citizen have a constitutional remedy?

Such ambiguities demand some clarifications. Welfare rights recognised by the ruling principles of social and economic policy can only be pleaded before ordinary courts according to the law. If the legislator does not legislate, it violates the Constitution by omission, yet no direct, legal remedy exists to force it to do so. Such an omission may be denounced by a particular institution – for example, the Ombudsman, or even the Constitutional Court – but this type of criticism is not legally binding. The rights to individual and collective petitioning are other possible tools, but technical difficulties in their implementation make them of little effect. In addition to these technical limitations, there are also budgetary and administrative restrictions to be considered.

The problem that then emerges is whether legislation regressive to welfare rights can be considered as unconstitutional. In other words, are there limits on the legislator and does the Supreme Court have the power to act if it considers those limits to have been exceeded? I understand that constitutional law can repeal those precepts that directly or indirectly violate welfare rights of any kind. Since constitutional law must be pleaded or petitioned by agents authorised to do so, one would have to wait for the initiative of such institutions, especially those that do not depend upon executive power, i.e. the Ombudsman, groups of congress members or senators, or, in certain hypothetical situations, regional governments and parliaments.

The Spanish Constitution is a flexible and ambiguous governing document that allows for numerous interpretations and various public policies. A social policy that reduces the scope of application of welfare rights could not be declared unconstitutional and is instead considered a policy choice, which, like any other, is arguable from a political point of view, but cannot be annulled from a legal point of view. Therefore, the Supreme Court would not be able to annul statutory provisions that restrict the potential effectiveness of welfare rights, unless legislative action sought to destroy the framework of welfare protection that our legal system has already consolidated. Implementing legislation in a way that reduces welfare rights must be interpreted restrictively, and if there are no other offsetting benefits, the Court could act in order to prevent a dismantling of the Welfare State. Moreover, it could declare as unconstitutional those provisions that breached the principle of equality by allowing a heavy burden to fall upon a determined group of citizens, or that enabled public authorities to make decisions on certain welfare benefits or activities, but did not ensure that they would be carried out by means of appropriate legislative action.

One must remember that ordinary courts can raise the *question of unconstitutionality* when they consider that the application, to a particular case, of a rule that violates fundamental principles of economic and social policy, would undermine or annul a constitutionally guaranteed social right. The possible annulment of regressive social legislation has significant limitations but also offers mechanisms for taking action, and the greater or lesser effectiveness of this control will depend upon the balance of political, economic, and social forces behind such legislation.

III

According to the system of guarantees in the Spanish Constitution, the "right to health care" recognised in Article 43.1, and the mandate for public authorities to maintain a public Social Security administration, found in Article 41, upon being included in Chapter III of Section I, ("of Guiding Principles of Social and Economic Policy"), it does not follow, in principle, that they can be used before the ordinary courts to directly claim protection from the State or third parties. As previously mentioned, in the way that they orientate positive legislation, judicial practice, and administrative action (as established in Article 53.5), they are of direct application and do not require subordinate legislation: in other words, they serve a direct interpretative function.

However, their function is not limited to an interpretative one. As stated in the Constitutional Court judgement (STC 80/1982) of December 20, they are also endowed with a certain regulatory power, although they to not have the legislative structure typical of legal regulations. The principle of "right to health care" is not the mandate, but the foundation criterion or justification for the mandate. Thus they exert their influence on later decisions (positive function), and exclude opposing values, and the regulations that rest on those values (negative function). They cannot go unrecognised by ordinary legislation which, if this occurs, could be contested as unconstitutional. However, the rights recognised in these guiding principles, as in the case of health protection, are not in a strict sense, subjective rights, but objectives that justify certain public policies. They can only be applied in the ordinary courts in accordance with the provisions of the laws that put them into effect, their effectiveness being subject to the provisions of the laws. A subjective right that requires the law to make it valid in court is only a legal right, not a fundamental or constitutional right. In contrast, the rights derived from these guiding principles can be invoked in the constitutional processes which are directed at controlling regulations (appeals against unconstitutionality) or the resolution of disputes over competence.

In addition to these federal responsibilities, the Welfare State adds others designed to create living conditions that neither individuals nor groups can create for themselves. Undoubtedly there is an assumption that the individual is not entirely able to take care of his health. This is evident if the collective aspects inherent in such care are considered, and it is no less evident when personal aspects are considered, such as illness or accident, the costs of which could extend far beyond the normal provisions of the individual.

STC 32/1983 of April 28 concluded that the Constitution "in Articles 43 and 51 … recognises the right to health care." The court went on to declare that "it is the duty of public authorities to organize and defend public health," and stipulated that "public authorities guarantee the defence of consumers and users by protecting their health," Further on, the judgement goes on to insist that the rights recognised by the Constitution in Articles 43 and 51 belong to all Spaniards and that everyone is guaranteed by the State equality in the basic conditions for their exercise. The State has exclusive jurisdiction to regulate the basic conditions that guarantee the equality of all Spaniards in exercising these rights and the fulfilment of constitutional obligations.

The Constitution has established a correlation between citizens' right to health care and the duty of public authorities to provide that service. This translates into a very specific obligation for the administration to maintain a social security system (which may contradict the idea of welfare rights as something conceptually different from civil and political rights). But the mere use of the term "rights" is not enough: The technical category of "subjective rights" is difficult to reconcile with what Article 43.1 sets out to do.

Article 41 of the Constitution gives public authorities a mandate to maintain a public system of social security, a system that already includes health benefits viewed as rights. Alone, an individual encounters great difficulty utilising coercive mechanisms to ensure that these constitutional obligations are fulfilled. However, what these constitutional obligations establish is a legitimisation of public intervention and support in certain social relationships. Thus, the barriers between the right to health care and the obligation of public authorities to maintain a system of social security are being broken down. What remains is an order of constitutionally protected objectives and values, among which is found the materialisation of the public good of health, which clearly restricts public authorities' sphere of operation. The obligations that these programmatic regulations establish for the legislator are of a political nature. The principles they incorporate must inform the legislation, which thus has to ensure that the reality is in line with the guiding principles. The regulation of such precepts is not in the style of "legal obligations", but that of statements attributing competence or authority. These regulations are legal, and relevant in the constitutional court of law, because they grant the legislator the capacity to intervene in certain economic and social areas, also guaranteed by the Constitution, and to introduce exceptions or limitations, in order to accomplish the pertinent objectives, and to avoid any possible dispute over legitimacy. No legal regulation can be judged according to the degree to which it follows, or does not achieve the objectives set by a programmatic regulation. Such objectives must inform the legislative function, but this requirement lacks legal sanction. One thing is the objectives of legislation, and another is the ends by which the Constitution determines the adoption of certain legal regulations. The constitutional objectives orientate the action of public authorities, but do not determine exactly when the action is taken. Whilst the link with objectives sets a commitment or task for public action – obtaining, in time, a certain result – the constitutional regulations that protect such tasks do not allow the degree to which the legislation is completed, to be judged. The objectives are reached through policies in which are inscribed definite, specific regulations, and as such, the policies are difficult to control legally. Programmatic regulations, in as much as they express heterogeneous requirements, must be the object of a consideration, or adjustment of a political nature, a task which lies outside jurisdiction. Such is its scope, and also its limit.

For this reason, I believe that the expression *right to health care* found in Article 43.1 of the 1978 Spanish Constitution can be better understood if we take into consideration that this is not a new right, but rather an extension of a pre-existing Constitutional obligation to protect health. In this sense, we must emphasise that the subjects protected under the social security system are entitled to compel public authorities to take the necessary measures to protect health. Thus, it becomes impossible to separate what is understood as the right to health care from social security.

One cannot ignore, as Aparicio (1989) maintains, the mandate found in Article 41 of the Constitution for public authorities to maintain a public Social Security administration, a system that views health benefits as rights. This mandate is a constitutional obligation, although, as we have already witnessed, the individual still finds it difficult to get hold of the coercive tools needed to force public authorities to meet their constitutional obligations. Essentially, these constitutional obligations allow public authorities to step in and manipulate certain social relationships for the common good. In this manner, the right to health care and the obligation of public authorities to maintain a system of social security become interwoven, which together must be contemplated as the embodiment of the federal goal, that is the State of *health,* understood as a basic constitutional principle.

ACKNOWLEDGEMENTS

This contribution is part of a wider research project lead by Universidad de Castilla-La Mancha, with the sponsorship of the Ministry of Science and Technology, entitled *Negotiation and Argumentation in the Decision Making Procedures of Democracies*.

NOTES

1. This essay was written before the last general Spanish elections on March 14th 2004, from which the Socialist Party emerged victorious and formed the new government after a period of conservative rule. It is hoped that Spanish public policy will change.
2. See Mishra, R. (1992), for all definitions. Another well-known approach is the triple model of the welfare system, as explained by Espring- Andersen (1993 and 2000): the *Anglo Saxon liberal* model, which promotes a selective and supplementary system based upon the economy; the *conservative or corporate* model, which promotes a paternalistic and subsidiary system based upon the family; and

the *Social Democrat or Scandinavian* model, which promotes a universal and egalitarian system, based upon citizenship.

[3] Such social problems are collective costs that, by their own nature and due to problems such as free riding or rationalised strikebreaking, cannot be solved by way of individual solutions.

[4] It is quite true that the legal constitutional protection of the two types of rights is not the same and that the Constitution reserves distinct mechanisms for jurisdictional protection, as I will later show.

[5] Economists have called this problem a question of *externalities*: when Adam Smith theorised on the free market, he imagined an economy composed of numerous isolated individuals, each one preoccupied with looking out for his own interests, without any reciprocal interference. In real life, this is not so: one's activity of production and consumption most likely affects others in very different ways, as much positively as it does negatively.

[6] Regarding the concept of rights in subjective terms, see Páramo (1996).

[7] In this paper, I follow Gil Calvo (1994) in my elaboration of these three effects.

[8] The three phases have been described by Alber (1983) and maintain a close relationship with the three possible models of welfare policy as analysed by R.M. Titmuss (1988): the model of supplementary assistance, the industrial model of yield-output, and the institution-reallocation model. The first one rests on the premise that two natural channels exist – the family and the economy – through which the needs of the individual are adequately and regularly satisfied (for which assisting intervention is an unusual and subsidiary exception). By contrast, the second sustains that the level of satisfaction of one's needs must depend upon merit, performance, and productivity, and its promotional function entrusts itself to the same businesses that reward the diligent and punish the lazy. Finally, the third model assigns an assisting-reallocating function to public officials: mechanisms of assistance are conceived as an institution based upon the principle of need, and the object of welfare policy is the long-term distribution of the control over the resources.

[9] In any case, if publicly financed activities end up leading to private benefit, this aid from the public treasury must be reintegrated from the moment such benefit is produced.

[10] Named after the apostle who quoted Jesus in the following Bible verse: "For to those who have, more will be given, and they will have abundance; but from those who have nothing, even what they have will be taken away" (Matthew 13: 12).

[11] This is what is known as the rationalised parasitism of free riding: when a person counts on the possibility of benefiting from the collective action of others without paying the price of participating, he has a great incentive to behave selfishly, that is, to behave as a true sponger. (Olson 1965).

[12] A general summary of this can be found in Contreras (1994); in reference to constitutional protection see Cascajo (1988).

REFERENCES

Alber, J. (1983) L´espansione dei Welfare State in Europa Occidentale:1900–1975, *Rivista Italiana di Scienza Politica* 12, 204.

Aparicio, J. (1989) *La seguridad social y la protección de la salud*, Civitas, Madrid.

Cascajo, J.L. (1988) *La tutela constitucional de los derechos sociales*, Centro de Estudios Constitucionales, Madrid.

Contreras, F.J. (1994) *Derechos sociales: teoría e ideología*, Tecnos, Madrid.

Esping-Andersen, G. (1993) *Los tres mundos del Estado del bienestar*. Edicions Alfons el Magnànim, Valencia.

_____. (2000) *Fundamentos sociales de las economías post-industriales*, Ariel, Barcelona.

Gil Calvo, E. (1994) Los derechos sociales. *Revista del CIFA* 13, Diputación de Barcelona.

Holmes, S. and Sunstein, C.R. (1999) *The Cost of Right: Why Liberty depends on taxes*, W.W. Norton, New York.

Mishra, R. (1992) *El estado de bienestar en crisis*, Ministerio de Trabajo y Seguridad Social, Madrid.

Olson, M. (1965) *The Logic of Collective Action*, Harvard University Press, Cambridge, Mass.

Páramo, J.R. (1996) Derecho subjetivo, in Garzón Valdés, E., & Laporta, F. (eds.), *El Derecho y la Justicia*, Trotta, Madrid, 367–394.

Titmuss, R.M. (1988) *Social Policy*, 5th ed., Unwin Hyman, London.

WAYNE VAUGHT

CHAPTER 9
AUTONOMY AND THE RIGHTS OF MINORS

Recognizing that minors, particularly adolescents, are often capable of engaging in medical decision-making long before they are legally considered adults, health professionals regularly struggle with the role that children and adolescents should play when faced with treatment decisions. In the United States, state laws now recognize a limited right for minors not only to participate in but to make certain treatment decisions on their own. The recognition of such rights challenges the traditional role of parents who were once entrusted with sole decisional authority. When should minors be permitted to make treatment decisions? When minors possess the capacity necessary to make treatment decisions, do parents and health professionals have an obligation to respect their wishes?

I begin with a review of several factors related to the rights of minors as decision-makers. I then outline the arguments in opposition to this trend, which favor the rights of parents as final decision-makers. Finally, I suggest that these arguments ultimately fail to take into consideration the wide range of difficult decisions minors may face, the variety of familial circumstances within which minors are raised, and the ethical obligations that health professionals have toward their adolescent patients. I argue that in cases where minors possess x, parents and health professionals have a *prima facie* moral obligation to respect their treatment decisions.

MINORS AND THE QUESTION OF DECISIONAL CAPACITY

The principle of autonomy and the closely related doctrine of informed consent, widely accepted in the United States as a fundamental right for patients, requires that health professionals show respect for the informed and voluntary treatment choices of their patients. Patients are capable of making treatment decisions when they possess the decisional capacity necessary to make informed and meaningful treatment decisions. When in possession of such capacities, their decisional authority, that is the *right* to have their wishes respected, is generally held to follow from a health professional's obligation to respect patient autonomy.

Historically, children were excluded from medical decision-making. Often, they were considered the chattel of their parents, particularly the father. "Accordingly, a father had the right to sue a physician who treated his son or daughter without his permission, even if the treatment had been perfectly appropriate, because such an intervention contravened the father's right to control his child (Holder 1989, 161)." Decisional authority rested solely with the parents, regardless of the minor's decisional capacity yet minors are no longer considered the legal property of their parents and there is growing debate surrounding the

D.N. Weisstub and G. D. Pintos (eds.), Autonomy and Human Rights in Health Care, 111–122.

appropriate limits of parental control in medical decision-making. Some advocates, acknowledging the legitimacy of the relationship between decisional capacity and decisional authority, argue that parental control should decrease and the minor's control should increase, as the minor's capacity develops. An adolescent's decisional authority has been recognized under common law in several recent court decisions (See for example: *In re* E.G., 133 Ill2d 98, 103 (1989), and *In re Crum*, 580 NE2d 876 (1991)).

One challenge to increasing a minor's decisional authority stems from concerns regarding their capacity to participate in medical decision-making. As Robert Weir and Charles Peters suggest (1997, 29), "many still doubt the capacity of adolescents to make the truly important decisions that sometimes confront them." In light of this perceived deficit, parental consent is generally sought prior to initiating medical treatment. However, this general presumption of incapacity, especially for older adolescents, increasingly is becoming suspect.

One factor motivating the trend toward increasing respect for a minor's right to medical decision-making stems from studies in developmental psychology. These studies tend to suggest that minors often do have the decisional capacity necessary to make most of their health care decisions by the time they reach the age of 14 or 15. A classic and frequently cited study by Thomas Grisso and Linda Vierling (1978, 412), for instance, found "little evidence that minors of age 15 and above as a group are any less competent to provide consent than are adults." Sanford Leikin (1989, 173) reports similar findings, suggesting that:

> by age 14 years, many minors attained the cognitive developmental stage associated with the psychological elements of rational consent. Furthermore, there appears to be no psychological grounds for the general assumption that minors 15 years of age or older cannot provide competent consent.

These studies indicate that minors often have the capacity to make rational treatment decisions several years before they reach the legal age of majority.

LEGAL AND PROFESSIONAL CONSIDERATIONS REGARDING MINORS' RIGHTS

The Council on Scientific Affairs of the American Medical Association (1992a, 1423) "encourages physicians to allow emancipated or mature minors to give informed consent for medical and psychiatric care without parental consent and notification, in conformity with state and federal law." In the United States, state statutes do provide some recognition of a minor's decisional authority. As Isabel Traugott and Ann Alpers point out, "the law provides several mechanisms to allow adolescents to consent to medical treatment without parental notification or consent." (1997, 924) For example, health professionals are permitted to render appropriate medical care in emergencies even when the parents are unavailable. Additionally minors may often give effective consent for birth control, the treatment of sexually transmitted diseases, psychological counseling, and substance abuse.

Concerns that minors might elect to forgo necessary medical attention are legitimate. The need to provide minors with access to confidential medical treatment is supported in a study conducted by Tina Ching (1993, 1405). She found that 57.9%

of the minors who participated in her study indicated that there were some health concerns that they would not want their parents to know about. Furthermore, 25.3% of the minors claimed that, in these circumstances, they might not seek care if they knew that their parents would find out. A survey conducted by A. Marks et al. (1983, 456–60) found that only 45% of adolescents would seek treatment for depression, 19% for birth control, 15% for sexually transmitted diseases, and 17% for drug use if parental consent was mandatory.

In addition to minor treatment statutes, which allow minors to give consent for certain specified services, a growing number of judicial rulings tend to support the right of older, more mature minors to give consent to a wide range of medical services. These judicial rulings have given rise to what is known as the "mature minor rule." This rule is based on the fact that there have not been any successful cases of a parent suing a physician for providing appropriate medical treatment, that was for the minor's benefit, when the minor seemed mature enough to give consent for the treatment. As Angela Holder suggests, "if a young person (of 14 or 15 or over) understands the nature of the proposed treatment and its risks and can give the same degree of informed consent as an adult patient, and the treatment does not involve very serious risks, the young person may validly consent to receiving it." (1989, 163)

While most of these cases dealt with adolescents who were consenting to beneficial medical treatment, in at least one case the court ruled in favor of a minor's right to refuse unwanted life-saving medical treatment. In 1989, the Illinois Supreme Court heard a case which involved:

> A 17-year-old female patient with leukemia [who] refused to consent to a blood transfusion on the basis of her religious beliefs. She, not her parent, had independently refused the transfusion, although her mother's religious views were similar to hers. A psychiatrist who examined the patient testified that she had the maturity of an 18 to 21-year old person. The juvenile court made a finding of medical neglect and had a guardian appointed, who consented to transfusions. The case was appealed and the Illinois Supreme Court held that if there is convincing evidence that the minor is mature enough to appreciate the consequences of her actions and to exercise the judgment of an adult, then she has the right to consent to or refuse medical treatment. (Sigman 1993 523)

This case is significant in that it lends support to the right of a minor, with decisional capacity, to refuse unwanted medical treatment, even when failure to provide such treatment may be life-threatening.

Finally, professional health organizations now support the right of mature minors to make their own treatment decisions. The American Medical Association for instance, in its *Code of Medical Ethics* states that "physicians who treat minors have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities." (2000–01, 53) Similarly, the American Academy of Pediatrics states that,

> patients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable. Furthermore, parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons. In all cases involving emancipated or mature minors with adequate

> decision-making capacity, or when otherwise permitted by law, physicians should seek *informed consent* directly from patients. (1995, 314–7)

CHALLENGES TO MINORS AS DECISION-MAKERS

One area of controversy regarding minor's rights pertains to their access to contraceptive services. The seeds for such a right were planted in the landmark U.S. Supreme Court case of *Griswold v. Connecticut* (381 U.S. 479, 1965). In this case, the Supreme Court declared unconstitutional a Connecticut law that denied married adults the right to obtain prescription contraceptives. It was not until 1977, however, in the case of *Carey v. Population Services International* that the court established the right of contraceptive privacy for minors (431 U.S. 678, 1977). In *Carey*, Justice Brennan claims that: "The right to privacy in connection with decisions affecting procreation extends to minors as well as to adults, and since a state may not impose a blanket prohibition, or even a blanket requirement of parental consent, on the choice of a minor to terminate her pregnancy, Planned Parenthood of Missouri v. Danforth, 428 U.S. 52, the constitutionality of a blanket prohibition of the distribution of contraceptives to minors is a fortiori foreclosed"

While *Carey* prohibits states from instituting a blanket prohibition, there has been ongoing debate at the federal level over the rights of minors to receive contraceptives through Title X of the *Public Health Services Act*. In 1970, the United States Congress provided minors access to confidential contraceptive services through Title X. In 1981, the Act was amended to "encourage family participation." The Reagan administration then attempted to require parental notification for any minor who received contraceptive services. This requirement was subsequently ruled unconstitutional. Fifteen years later, On July 30th and October 7th, 1998, the United States Senate and House of Representatives, respectively, introduced legislation aimed at limiting the right of unemancipated minors to receive contraceptive services without parental consent or notification. These pieces of legislation specifically targeted minors who were otherwise eligible to receive services under Title X of the *Public Health Service Act*. According to Senate Bill 2380, introduced by senator Aschcroft:

> all federally funded programs that provide for the distribution of contraceptive drugs or devices to minors, or that provide abortion referrals to minors, are, except as provided in subsection (b), required to obtain informed written consent of a custodial parent or custodial legal guardian of a minor prior to the provision of contraceptive drugs or devices or abortion referral information to the minor.

Similarly, H. R. 4721, introduced in the House of Representative*s* by representatives Istook et al. sought to deny funds, appropriated according to Title X of the *Public Health Service Act*, to any provider who knowingly provides contraceptive drugs or devices to a minor without (1) providing written notification to the parents, or (2) receiving written consent from a parent or (3) the minor being emancipated, or (4) a court order authorizing such distribution to the minor. While these bills ultimately died in committee and were not brought to the floors of either the senate or house for a vote, they are indicative of the current and ongoing controversy in health care policy pertaining to the rights of unemancipated adolescents.

The spirit of such legislation is reflected in the work of ethicist Lainie Freidman Ross who argues against the rights of minors in medical decision-making (1997, 41–5). Ross challenges the position taken by the American Academy of Pediatrics in an article entitled Health Care Decision Making by Children: Is it in Their Best Interest?" In this article, Ross argues that we must reconsider the appropriateness of granting minors the right to make their own treatment decisions. She claims that in spite of recent studies into adolescent capacity, it is difficult, if not impossible, to determine whether any particular child has sufficient decisional capacity to make meaningful treatment decisions. However, unlike those who would deny that minors have decisional capacity, Ross argues that even when they have capacity it is misguided to grant them decisional authority. Capacity, Ross claims, "is a necessary but not a sufficient condition on which to base respect for a minor's health care decision making autonomy" (1997, 41).

Three main themes arise out of Ross's critique of minors as medical decision-makers. First, Ross claims that allowing minors to make treatment decisions places too much emphasis on "present-day-autonomy" and not enough emphasis on "life-time-autonomy." She contends that a "child's decisions are based on limited world experience and so are not part of a well-conceived life plan" (1997, 42). She is not alone in voicing this concern. Dan Brock, for instance, cautions that one difficulty with minors as decision-makers stems from their limited conceptions of their good. "An important issue," Brock suggests, "is whether their values adequately reflect their future interests" (1989, 186). Ross suggests that minors should not be allowed to make any decisive treatment decisions that could adversely impact on their options in the future. Rather, she feels that parents are in a better position to protect their children's "life-time" autonomy.

Second, Ross suggests that, given the "significant role that intimate families play in our lives . . . parents should have wide discretion in pursuing family goals, goals which may compete and conflict with the goals of particular members" (1997, 43). Accordingly, allowing minors to give effective, and exclusive, consent for prescription contraceptives, abortions, or other treatment decisions may circumvent legitimate parental rights.

Finally, Ross takes issue with a position supported by the American Academy of Pediatrics which states that "in cases of serious conflict [between the parent and the child], physicians and families should seek consultative assistance and only in rare circumstances look to judicial determinations" (1995, 314). Ross argues that seeking consultative assistance, or mediation, only serves to "undermine the family" by denying them the "moral and legal space within which to make decisions that will facilitate their child's long-term autonomy" (1997, 44). In cases of disagreement between the parent and the child, Ross claims that "the child's decisions should not be decisive nor should health care providers . . . seek third party mediation. Rather [Ross believes that] . . . the parents should have final decision making authority" (1997, 44).

Ross raises several important concerns that are perhaps relevant in many circumstances. If her arguments hold, they pose a serious challenge to those who seek to increase the rights of minors by granting them decisional authority. However, I find her overall position untenable. In the remainder of this paper, I will explore these arguments in greater depth and show why they ultimately fail to provide a blanket justification against the decisional authority of certain minors.

PEDIATRIC DECISION-MAKING AND "LIFE-TIME" AUTONOMY

One of Ross's primary arguments against decisional authority for minors stems from a distinction she makes between "present-day" autonomy and "life-time" autonomy. She argues that "life-time" autonomy (ones ability to make autonomous decisions over one's lifetime) must take precedence over "present-day" autonomy (one's ability to make an autonomous decision today). She then suggests that while minors may possess "present-day" autonomy they may lack the ability to protect their "life-time" autonomy. It is the responsibility of the parents, Ross claims, to protect the minor's "life-time" autonomy from the minor's "present-day" autonomous self. Thus, minors' "present day" autonomy need not entail their right to make their own treatment decisions. This argument, however, is problematic.

First, an autonomous agent is an individual who is capable of making reasoned decisions based on his or her own values and beliefs. Beauchamp and Childress classify autonomous agents in terms of "normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influence that determine their action" (2001, 59). They suggest that a "patient or subject has the capacity to make a decision if he or she is able to understand the material information, to make a judgment about the information in light of his or her values, to intend a certain outcome, and to freely communicate his or her wishes to caregivers or investigators" (2001, 71).

Ross, I believe, trivializes the significance of "present-day" autonomy for minors by appealing to an example of an adolescent who refuses medication because it requires the use of needles. "Imagine" she suggests, "that a fourteen-year-old with new-onset diabetes refuses to take insulin because she fears needles. ... Who is willing to abandon her to her autonomy?" This, it seems, is a particularly weak example of respect for adolescent autonomy (1997, 44). If, as Ross seems to suggest, such an individual lacks a well-conceived life plan within which to make this decision, or is making a rather frivolous decisions without giving adequate consideration to the long-term consequences of the act, then it seems inappropriate to refer to this as an autonomous choice in the first place.

An individual's ability to make meaningful health care decisions must be considered in the context of the decision to be made. Capacity determinations require a match between the demands of the situation against the individual's current abilities. To say that an individual is "presently" autonomous is to say that he or she currently has the capacity to consider the elements necessary to make a meaningful decision. "Present-day" autonomy, properly understood, would seem to necessitate the ability to make use of relevant information, including information regarding how a decision will affect us in the future, if such consideration is necessary. In this way, Ross's introduction of the concept of "life-time" autonomy distorts the question of what is at issue for a presently autonomous agent.

Even if we were to accept Ross's distinction between "present-day" and "lifetime" autonomy as legitimate, it is not clear that it would establish the priority of parental decisions over those made by a minor. There may be circumstances that necessitate giving priority to a minor's decisions. For instance, in some circumstances, particularly during end of life care, parents may request that a physician withhold certain information from their child. Such a request may seem perfectly justifiable because parents have, as Sandford Leikin points out, "an overwhelming wish to protect a very sick child from disturbing information." Parents tend to fear that informing a child of a terminal condition, or a grim prognosis, may be psychologically overwhelming, so they tend to try and fulfil their obligation to protect their children by limiting their access to this information (1989, 18).

While most caring parents want to protect their children from unnecessary pain, either physical or psychological, health professionals must consider parental requests to withhold information in light of the harms associated with non-disclosure and the patient's desire to have access to that information. If a minor disagrees with his parents, and wants to participate in treatment decisions, should health professionals consider the parents' decision to exclude their child as final? There are at least two arguments that can be used against so excluding children.

First, it is unclear that withholding information from children, particularly those suffering from a terminal condition, will protect them from unwanted suffering. In an important work on this subject, Myra Bluebond-Langer (1978) studied children in oncology units who were suffering from Acute Lymphocytic Leukemia. Of her findings, compiled in a work entitled *The Private Worlds of Dying Children*, several observations are relevant to adolescent decision-making. First, Bluebond-Langner noticed that children in the oncology unit were more aware of what was going on around them than either their parents or members of the health care team believed (1978, 136–7). For instance, she noted that "the children were well aware of the multiple purposes hospital rooms served in addition to their designated function. ... Many of the children commented on how it seemed that 'if the doctor does not want your mother around, he takes you to the treatment room.'" Their observation accurately reflected the attitudes of many of the physician's who claimed that "they preferred carrying out procedures in the treatment room, because it was easier to keep the parents out and the children were easier to manage" (1978, 136–7). No one had explained this to either the children or the parents.

More importantly, the children in Bluebond-Langner's study understood their disease and its treatment, process, and prognosis. They understood the nature of their treatment, the purposes of individual medications, and for many, that they were going to die. Some of the children in Bluebond-Langer's study stated outright that they knew they were going to die. Others would less directly refer to the possibility of their death by indicating that they would "not be going back to school" or "not being around for a friend's birthday party." According to Bluebond-Langer, "all [of the children] knew that they were dying before death was imminent (1978, 165).

What is most troubling regarding this study is the fact that the children were not only aware of their own conditions and prognosis, but they also realized that their parents, and often members of the health care team, were uncomfortable discussing it. In some circumstances, the resistance was obvious. For example, Bluebond-Langner found that "if the children asked questions that might force the staff to reveal the prognosis, (e.g., what happens when the drug runs out) the staff members showed their unwillingness to talk about the matter by leaving the room, reprimanding the children, or by simply ignoring the question." Instead of confronting the issue in these situations, the children, parents, and staff engaged in an act of what Bluebond-Langer refers to as "mutual pretence"; each side wilfully avoiding a discussion of the undesirable possibilities, in order to protect the other (1978, 201).

While "mutual pretense" may make the interaction with the patient seem easier, as they no longer have to discuss the patient's poor prognosis, it is not clear that it makes the child's personal experience of disease any easier. In fact, in such cases the child is unable to express any of his or her feelings about death nor actively participate in end of life decision-making. As a result, these children may spend the last days of their life feeling very much alone and abandoned. James and Hilde Nelson in their book, *The Patient in the Family*, emphasize that "it takes courage to tell a five-year-old that she will soon die, but if this is not done the child faces death alone, with the additional burden of cooperating in a conspiracy of silence that requires her [the child] to take care of her caregiver's feelings" (1995, 103).

Second, it is not clear that Ross can sustain her argument against interfering with parental decisions in light of her emphasis on "life-time" autonomy. For instance, in a case reported in the *American Journal of Diseases of Children*, a young girl was diagnosed with Cystic Fibrosis. Like many of the parents in Bluebond-Langner's study, they were very upset and demanded that she not be told. The physician in this case agreed to the parent's request assuming that he would eventually be able to change their minds. He was not. According to Sigman, it was not until the girl was 18, and still against parental objections, that she was given the name of her condition and informed of the long-term prognosis (1993, 764–8).

While Cystic Fibrosis once killed a majority of its victims early in adolescence, current therapies allow patients to live well into adulthood. The physician, and her parents, would have to recognize that the girl would most likely become an adult. It would seem irresponsible, and ethically questionable, to withhold information from this girl as her capacity developed. Respect for autonomy entails some obligation to assist individuals into becoming autonomous agents. The parents' request in this case would certainly thwart that ability. Given the importance of "life-time" autonomy, the health care team may need to intervene and force the parents to allow disclosure, especially if the child is requesting access to that information.

Ross is not; I should point out, arguing that minors should be excluded from treatment decision-making. Ross clearly states that she does "not mean to suggest that children, particularly mature children should be ignored in the decision-making process." Ross emphasises that their inclusion should merely be used to "help them understand what is being done to them and to garner, when possible, their cooperation." However, whenever there is a conflict between the parents and the child, she believes that the parents', not the child's, decision should be decisive (1997, 44).

Finally, the distinction between "life-time" and "present-day" autonomy is not particularly useful in situations where a minor's treatment decisions will not significantly impact his or her future autonomy. Suppose that a sixteen-year-old patient, after several months of treatment, believes that burdens of aggressive treatment, which may offer at most a few weeks or months of life, far outweigh its benefits and decides to discontinue such care. If the minor has capacity, is able to understand his or her prognosis and the consequences of the decision being made, it seems irrelevant to introduce the concept of "life-time" autonomy where "present-day" autonomy is all that is required. While a parent may wish to preserve every possible moment of their child's life, the autonomous minor ought to have the right to refuse unwanted care.

There are several reasons to reject Ross's argument that denies decisional authority to minors based on her emphasis on lifetime autonomy. First, distinguishing between "life-time" and "present-day" autonomy does not help us to better understand what is required of a decision-maker. The very concept of autonomy entails the ability of a person to consider the future impact of their decision; and, some minors do seem capable of making such decisions. Second, acknowledging the importance of "life-time" autonomy in certain circumstances may provide legitimate justification for interfering with a parent's decisions, especially if those decisions interfere with the minor's well being or development into an autonomous agent. Finally, there are many relevant decisions that minors may face where an emphasis on "life-time" autonomy is irrelevant. Ross's emphasis on "life-time" autonomy does not adequately support a blanket argument against a minor's right to make treatment decisions.

PEDIATRIC AUTONOMY AND PARENTAL RIGHTS

I now want to turn to a second theme in Ross's argument, that of parental values in medical decision-making. Ross argues that health professionals have an obligation to respect the role of the family in the minor's development and to avoid interfering with legitimate parental rights. However, Ross does not take into consideration the wide range of familial relationships that mature minors may have with their parents. These relationships are not always beneficial. Some parents are abusive. In these cases, denying teens the right to make decisions regarding such issues as reproductive health may significantly increase the risk to their health and wellbeing.

Parents do have a wide range of decisions that they can control, to some degree. However, such control cannot always carry over to medical decision-making. Consider the following case involving a minor's refusal to participate in a non-therapeutic research protocol. For the study, healthy volunteers were needed to donate a small amount of blood. When approached for possible participation, a small boy declined, saying that he didn't want to get stuck with any needles. According to the account by Willard Gaylin, the boy's father then ordered his son to stick out his arm and allow the doctor to take some blood. According to the father, it was

> his moral obligation to teach his child that there are certain things one does, even if it causes a small amount of pain, to the service or benefit of others. [The father stated that] 'This is my child. I was less concerned with the research involved than with the kind of boy I was raising. I'll be damned if I was going to allow my child, because of some idiotic concept of children's rights, to assume that he was entitled to be a selfish, narcissistic little bastard (1982, 29).

While I agree that there is value in teaching children to be sensitive to the needs of others and to accept certain amounts of discomfort for the benefit of others, there are some difficulties in using medical research to foster this goal. First, there are other ways for parents show their disappointment with the child's decision. Second, health professionals, and the health professions in general, have their own ethical codes and values that may prevent them from adhering to parental requests. For instance, it is largely held that a minor's *assent* is required before subjecting any child to a "non-therapeutic" research procedure, that is, any research that will not directly benefit the child. In this case, the parents' decision to include the child cannot be decisive, and the child's decision may prove decisive, as the parent's decision does not create an ethical obligation on the part of the health professional to adhere to the parents' request.

THIRD PARTY INTERESTS IN PEDIATRIC DECISIONS

Finally, Ross takes issue with the American Academy of Pediatrics' willingness to include third party mediation when conflicts arise between minors and their parents. Her position is problematic in that it would ultimately exclude concerned health professionals from their legitimate roles as patient advocates. Ross bases her argument against mediation on her concern for protecting the integrity of the family and parental rights and responsibilities. She argues that, "parental autonomy promotes the interests and goals of both children and parents. It serves the needs and interests of the child to have autonomous parents who will help him become an autonomous individual capable of devising and implementing his own life plan" (1997, 43).

We must be cautious in our use of autonomy in these contexts. Susan Sherwin cautions that "the concept of autonomy, rather than working to empower the oppressed and exploited among us, in practice often serves to protect the privileges of the most powerful. "The concept of autonomy is also exclusionary," Sherwin continues, "in that it is generally ascribed only to those persons who are recognized as rational." In practice, "rationality has historically been constructed in ways that exclude not only children, but also women and members of other oppressed groups." We should be careful not to construct autonomy in such a way that it arbitrarily excludes a vulnerable group of individuals (1996, 53).

Nevertheless, health professionals certainly need to be sensitive to the important role that parents play in a child's development. Children typically share special relationships with their parents which may continue long after medical intervention. As James and Hilde Nelson point out:

> families are also crucial to the formation of a child's conscience. If conscience is understood as 'the exercise and expression of a reflective sense of integrity,' as 'the voice of one's self as a whole,' which integrates personal history, reason, emotion,

> imagination, and action, then insofar as the family gives a child its sense of self, it gives the child the stuff of conscience (1995, 79).

Disrupting the bond and trusting relationship that the child has with his or her parents could have serious long-term consequences.

The need to preserve familial relationships does not exclude the appropriateness of mediation. Conflicts between parents and children over medical therapies can originate from a variety of sources. There may be confusion regarding the implications of a medical intervention, or lack thereof. Children, and their parents, could be attempting to exert themselves and establish some control, especially if the medical condition or environment makes them feel vulnerable. Or, the disagreement could result from underlying tension within the family. Through mediation, health professionals may be able to sort through some of these variables.

In certain circumstances, there may be legitimate conflicts of values. A parent's decision may reflect deeply held familial values or religious beliefs. When the child is young, and these decisions do not seriously compromise the health and safety of the child, adhering to their wishes may be appropriate. Mediation in these circumstances may help the health care team to better understand the parent's position and to ensure that they do not jeopardize the patient's health. In other circumstances, particularly when minors are older and able to articulate their own values, mediation may allow the parents and the patient to work through their conflict and come to a reasonable resolution.

Ross emphasizes the importance of parental "rights" in raising their children. She is opposed to mediation because she believes that it ultimately allows the values of health professionals to override those of the parents. Our concern should not, however, be one of substituting parental values for those of health professionals. Rather we must acknowledge that as minors mature, health professionals have an obligation to give serious attention to the minor's own treatment decisions. Mediation can bring all of these issues into focus.

CONCLUSION

There is growing recognition of the legitimate role that minors should play in medical decision-making. Prominent professional organizations now emphasize the importance of including children in medical decision-making and, in certain circumstances, granting them decisional authority. In so doing, it is essential that we give serious consideration to the familial circumstances from which minors come, and to which they may return, after their interaction with the medical community. While it is important that we take into consideration parental rights and responsibilities, it is also important that we appreciate the developing capacities of minors to make treatment decisions and the moral obligation that such capacities create on the part of health professionals and parents alike. When a minor is capable of making an autonomous decision, parents and health professionals are obliged to acknowledge a minor's right to make those decisions.

REFERENCES

American Academy of Pediatrics (1995) Informed consent, parental permission, and assent in pediatric practice, *Pediatrics* 95(2), 314–7.

American Medical Association (2000–2001) *Code of Medical Ethics: Current Opinions with Annotations*, The Association, Chicago.

Beauchamp, T. and Childress, J. (2001) *Principles of Biomedical Ethics* 5th ed., Oxford University Press, New York.

Bluebond-Langner, M. (1978) *The Private Worlds of Dying Children*, Princeton University Press, Princeton.

Brock, Dan. (1989) Children's competence for health care decision making, in Kopelman, L., and Moskop, J. (eds.), *Children and Health Care: Moral and Social Issues*, Kluwer Academic Publishers, Dordrecht.

Ching, T., et al. (1993) Confidentiality in healthcare: A survey of knowledge, perceptions, and attitudes among high school students, *Journal of the American Medical Association* 269(11), 1404–07.

Gaylin, W. (1982) Competence: No longer all or none, in Gaylin, W. and Macklin, R. (eds.), *Who Speaks for the Child: The Problems of Proxy Consent*, Plenum Press, New York, 27–54.

Grisso, T. and Vierling, L. (1978) Minors' consent to treatment: a developmental perspective, *Professional Psychology* 9(3), 412–27.

Holder, A. (1989) Children and Adolescents: Their Right to Decide About Their Own Health Care, in Kopelman, L., and Moskop, J. (eds.), *Children and Healthcare: Moral and Social Issues*, Kluwer Academic Publishers, Dordrecht , 161–72.

Leikin, S. (1983) Minor's assent or dissent to medical treatment, *Journal of Pediatrics* 102(2), 169–76.

_____. (1989) A proposal concerning decisions to forgo life-sustaining treatment for young people, *Journal of Pediatrics* 115(1), 17–22.

Marks, A., et al. (1983) Assessment of Health Needs and willingness to Utilize Health Care Resources of Adolescents in a Suburban Population, *Journal of Pediatrics* 102(3), 456–60.

Nelson, H. and Nelson, J. (1995) *The Patient in the Family: An Ethics of Medicine and Families*, Routledge, New York.

Ross, L.F. (1997) Health care decisionmaking by children: is it in their best interest? *Hastings Center Report* 27(6), 41–5.

Sherwin, S. (1996) Feminism and Bioethics, in Wolf, S. (ed.), *Feminism and Bioethics: Beyond Reproduction*, Oxford University Press, New York, 47–66.

Sigman, G., et al. (1993) Disclosure of a diagnosis to children and adolescents when parents object: a clinical ethics analysis, *American Journal of Diseases of Children* 147(7), 764–68.

Traugott, I., and Alpers, A. (1997) In their own hands: Adolescents' refusals of medical treatment, *Archives of Pediatric and Adolescent Medicine* 151(9), 922–27.

Weir, R. F., and Peters, C. (1997) Affirming the decisions adolescents make about life and death, *Hastings Center Report* 27(6), 29–40.

GEORGE P. PALERMO

CHAPTER 10
DOMESTIC VIOLENCE

Autonomy v. Control

INTRODUCTION

The tragedy of domestic violence will be touched upon in these pages. Domestic violence takes place in the sanctity of the home and involves intimate partners or other family members. Usually, it follows an emotional, verbal or physical confrontation between those involved. On the surface the reasons may be economic, social and affective, but at a deeper level it reflects a clash between autonomy and control. The desire for self-realisation, self-acceptance and respect are generally frustrated by the drive for dominance, and the violent impulsiveness of the stronger person, who tries to enforce a submissive or subordinate role on the other, brings about feelings of humiliation and despair in the weaker person. Often, but not always, the aggressor is a man – husband or cohabitant – and the victim is his wife, partner or child. Male domination expresses itself as physical or psychological abuse and intimidation of the members of a family, whether spouse or partner, children or the elderly. The control used to intimidate the victim may also be economic. Indeed, it typically extends to issues of money, to the victim's choice of friends, and to the persons they are allowed to communicate with.

Thus, in assessing domestic violence and the possible factors at its roots, autonomy and control/dominance should be taken into consideration and, more specifically, the drive for autonomy or self-determination of the members of a family, which may include spouses or co-inhabitants, children, grandparents and other extended family members.

BRIEF HISTORICAL NOTES

It is assumed that, except for brief periods of matriarchy in some cultures, the history of humankind has been dominated by a patriarchal system. Our early ancestors already divided household labour on the basis of biological differences: the males were the hunters and gatherers and the women cared for the children. Gender differences and the assertiveness of males supported their dominant role over women whose role was consistently viewed as linked to child-rearing and domestic activities. As time went on, different cultures perpetuated this gender inequality and women were increasingly viewed as non-political actors – at times virtually non-persons – as the property of men (Gregor 1990). They were seen as sexual objects, either within the domesticity of their homes or when assigned to particular roles in their communities (e.g., as prostitutes). Thus, women came to

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 123–141.

consider themselves as sexual beings and in many ways they capitalised on that at opportune times when, from an evolutionary point of view, the woman chooses a mate who will assure, through his physical, intellectual and social capacities, a better life for herself and her children. However, at the same time that women considered themselves as sexual beings, they also felt vulnerable. This vulnerability originated from man's self-conception of superiority in a male dominated society in which the women were regarded as intellectually, morally and spiritually inferior and at the mercy of man's ambivalence towards her, a mixture of aggression and protective love.

That a woman in her home was subordinate to the man in the past was almost a consistent social condition, except for brief periods. During the Kingdom of Hammurabi, for example, women seem to have had some specific rights. The Hammurabi Code, written almost 4,000 years ago, stated that women could own businesses and buy property, and if a man divorced a woman, she was entitled to the return of her dowry and the man was required to pay child support.[1] Nevertheless, the fact that women were rarely seen as equals but generally as inferior to men, is clearly present in some early Jewish writings, e.g., "Blessed art thou, O Lord our God, who has not made me a woman" (Davis 1998, 48; Stein 1993, 7). But as Richard Davis has written (1998), while early Christianity attempted to view women as equal to men, at least in the eyes of God, as in Galatians, 3:27: "... [t]here is neither male nor female; for you are all one in Christ Jesus," the ambivalence toward them is evident in I Timothy, 2:11–12: "Let a woman learn in silence with all submissiveness. I permit no woman to teach or to have authority over men; she is to keep silent." Interestingly, however, Proverbs 12:4 states: "A virtuous woman is a crown to her husband."

From early Sumerian, Jewish and Christian periods to the present, women have undergone physical, sexual, and social disparagement and tribulation. The abuse that they suffered within the walls of their homes over the centuries is not really known, but one can draw some conclusions in that regard from the fact that, as Davis reports, even in early America "a husband was legally permitted to chastise his wife without subjecting himself to vexatious prosecutions for assault and battery" (Davis 1998, 50). Since the 19th century, however, in the United States as well as in other countries, there has been an upsurge of women's formalised revolt against being viewed as second class citizens (Arnaud-Duc 1995).

The social equalisation of women, their protection from domestic abuse and their recognition as socio-political beings went through a century of progressive victories beginning with an 1871 Alabama court decision stating that "a wife had the right to the same protection of the law that the husband can invoke for himself."[2] The whipping post for wife beaters legislation in several states, the emancipation of women forced by circumstances during and after World War II, the equal pay law signed by President John F. Kennedy in 1960, and the feminist movement were all important events that helped bring about significant social changes. Nevertheless, even though women have more legal protections today and are recognised by the law as equal to men, the instances of physical and sexual assault remains at high levels within the domesticity of their homes.

STATISTICAL STUDIES

Marvin Wolfgang's 1958 study of violent deaths in Philadelphia from 1948 to 1952 revealed that in murders that take place within the home, the most common homicide is uxoricide followed by filicide. In his survey of the homicides that had taken place during that period, Wolfgang found that 25% involved members of the same family and that of 136 victims of homicide, 100 were wives and 17 were children of the murderer. "The largest categories, 28.2% of victims, were "close friends." The next largest (24.7%) were members of the family" (1958, 207). A later study reported in 1964 that either the wife or the husband were victims of aggravated aggressions in 11% of the cases studied (Pittman and Handy 1964).

In 1996, Murray A. Straus and collaborators reported that 6,100 married couples out of 100,000 had abused one another physically in a violent way during the year of their study. The study further pointed out that during the same period 1,800,000 wives had been seriously physically assaulted by their husbands at least once a year. In 1992, it was estimated that on the average, within a twelve month period in the United States, approximately 2,000,000 women were seriously assaulted by their male partners (Council on Scientific Affairs 1992a). Later studies pointed out that the above estimate was far below the possible 4,000,000 severely assaulted women.[3] Recent statistics show that almost 2,000 persons were victims of intra-familial violence resulting in homicide and non-negligent manslaughter in 1998 (Maguire and Pastore 1999, 290).

The Family. The rate of family violence has reached epidemic proportions in the United States. It is not restricted to any particular social or economic group, nor is sex, age or gender limiting factors. Recent statistics reveal that in 1997 the number of assaults in a home in the United States were 6,723,290 (15.1% aggravated and 14.4% simple). It is estimated that 7.5% of males and 24.8% of females are victims of rape and/or physical assault in which the victimizer is an intimate partner of the victim (Maguire and Pastore 1999, 191). Already in 1990, Richard J. Gelles and Claire P. Cornell had written, "People are more likely to be killed, physically assaulted, hit, beaten up, slapped, or spanked in their own homes by other family members than anywhere else, or by anyone else, in our society" (1990, 11).

In order to understand the agony and the despair suffered by the victims of family violence, one should be reminded of what any person, either at a conscious or an unconscious level, expects from his or her living within a family. My long professional experience with people who have struggled with emotional or existential problems allows me to state that the majority of people look upon, and expect, the family to be a nurturing and protecting micro-community. It is within the family unit, ideally an aggregate of people sharing similar backgrounds or strong physical and affective ties as well as interests that each individual expects to be loved, to be nurtured, to be able to acquire his or her own identity (individuation) and to be respected in his or her own privacy. The family is the fundamental unit upon which society is built. Its functions are basic and vital, and even though its structure has moved from a being fixed and static to becoming more flexible in order to assure the continuity of an evolving society – the *gesellschaft* of the German sociologists – its purpose remains that of bringing together diverse ethnic, social groups into harmonious functioning.

In searching for the etymological roots of the word domestic, defined as "relating to the household or the family,"[4] we are reminded that for the ancient Greeks, the word *domos*, and for the Romans, its equivalent *domus*, referred not only to the physical structure of a house but also to what today we call home; just as *domesticus* meant pertaining to the family. Violence, on the other hand, deriving from the Latin *vis* and *violentia*, is the intentional use of force exercised by one against another. The force may be physical, psychological or moral, and its purpose is usually to inflict physical harm, psychological pain or moral constriction. Usually, the violent action is a source of gratification for the victimiser.

With this semantic background we are better able to understand what domestic violence actually means to the aggressor and to the victim. When we talk about domestic violence we are referring to violence within the family with the specific intention of exercising control. I question, however, whether a dyscontrolled individual, and in this case, a violent one, is able to achieve control in such a situation other than through the short-lived frightening or intimidating effect on the victim. While not underestimating its importance in interpersonal relationships, I do not consider pertinent in this context, the occasional explosive expression of emotional feelings in the heat of an argument which is known as verbal violence. The definition of domestic violence must have at its core the intention of the victimiser to harm another member of his or her own family. Obviously, when using this particular definition the perimeter of the household must be extended to include the concept of familiarity among those persons having strong emotional and physical ties but who, for various considerations, live separately. Family violence may take place, therefore, outside of the family home.

Domestic violence in its various forms of aggression towards spouse, children and the elderly may be continuous, cyclical or sudden in its manifestations. Because family violence is often a recurrent situation and often unpredictable, even though usually specific in type, it is easy to understand the anxieties and the despair in the minds of the victims who wait in anxious anticipation for the next explosive physical act. The deleterious effect of family violence does not stop at the suffering and agony of the helpless victim, but tends to influence the present and future behaviour of all the family members. Indeed, it has been reported that over two-thirds of men who physically abuse their partners come from homes in which there was parental violence, and approximately half of the abusers, were, themselves, abused as children (Fitch and Papantonio 1983). Thus, violence appears to beget violence, to divide the members of the family into partisan groups, to create psychosomatic problems in both adults and in children. The behaviour of these children may at first be oppositional, but later in life may develop into antisocial psychopathic aggression. Extreme rage against parental figures, at times eventuating in the tragedy of murder, is often seen as the *sequelae* of continuous maltreatment (or, rarely, may be due to mental illness).

Sexual abuse consisting in spousal rape, sexual assault of biological children – usually girls – or of adoptive children by the man of the house is a frequently reported event, and at times contributes to adolescent or young adult drug addiction, alcoholism and prostitution. Sexual abuse comprises fondling of non-genital body parts, heterosexual and homosexual acts, molestation with genital contact such as cunnilingus, vaginal, oral, and rectal intercourse. "Rapes and other sexual assaults by husbands, former husbands, boyfriends, and former boyfriends make up about a fourth of all offences in this category, according to surveys of reported and unreported assaults throughout the United States" (Thornhill and Palmer 2000, 77). Faced with the above knowledge, one must wonder whether the retraction by Sigmund Freud of the possible sexual molestation of his female patients by their fathers was only a politically correct and convenient action on his part during that historical period, since we come across numerous cases of sexual assaults and incest/rape within the context of present day families.

TYPOLOGY

It is natural to wonder whether either the aggressor or the victim of family violence has particular psychodynamics which make this type of offence so recurrent. The family is, as a rule, housed in a structure the boundaries of which are well-defined and which is generally far from the scrutiny of neighbours or passers-by. The members of the family usually have strong emotional feelings towards one another, either positive or negative, at times ambivalent. No one could find a better laboratory for the study of emotions than in the family. It is within the family that the infant, the developing child – future adult – develops his or her primary, basic feeling self.

Criminal justice data show that men who are charged with domestic violence are often young; the majority are between the ages of 13 and 30. "This same correlation seems to be true for the victims. Women between the ages of 19 and 29 are more likely than other women to be victimised by an intimate" (Donzinger 1996, 158). Davis reports a study which found that "90% [of domestic violence abusers] do not have a criminal record, indicating the (sic) most offenders are not deviant outside the family" (1999, 19; Barri-Flowers 1996, 13). Nevertheless, a high degree of alcoholism and antisocial behaviour has been found among abuse husbands.

The persons involved in family violence usually have a particular type of personality. Generally, men who assault their female partners claim to have been subjected in childhood to sexual abuse, to have witnessed violence, and to have witnessed their father abusing alcohol and illicit drugs. They, themselves, have often done the same at a much higher rate than in non-abusive males. They are usually insecure and inadequate, and are poor achievers who feel incapable of living up to expected standards within a relationship. They also attempt to hide their incompetence as a provider or co-provider in the family. At times, arguing with a partner or other family members makes them acutely aware of their feelings of inadequacy and because of that they strike out against those whom they feel are threatening their marginal emotional homeostasis.

Melvin Lansky, in "Family Genesis of Aggression," states that shame is of central importance in the determination of impulsive and violent behaviour (1993). It is equated, he says, to humiliation and loss of self-esteem. He claims that some people have a particular proneness to shame that leads to excessive reliance on others for the maintenance of their self-esteem. He believes that this is due to having grown up in a dysfunctional family in which the child was made to feel inadequate. This person, as a result of these feelings of inadequacy and proneness to shame, is often filled with semi-repressed rage and acts out his or her hostile feelings. Indeed, it is not the well-balanced, self-assured, strong individual who strikes out at members of his family or at others, but rather the anxious, inadequate person who feels intimidated, powerless, shamed, and helpless. It is usually the weak who react in such a violent fashion, not the strong.

The person prone to violence, in order to avoid impulsive actions may use various defence mechanisms. One of these is to keep his spouse or other members of the family at a certain emotional distance; this is why some explosive people may appear to be emotionally detached and are often loners. Their rage is usually controlled by camouflaged behaviour, initiated as a protective mechanism to avoid feelings of shame or weakness.

THE VICTIMS

Wives and Partners. Several studies have been conducted in an attempt to define the characteristics of persons who are victims of marital violence. Interestingly, in a meta-analysis of 52 studies only one variable was consistently found to be a potential risk marker for women of becoming the victim of marital violence and that was “witnessing parental violence as a child or adolescent” (Council on Scientific Affairs 1992a, 3186). Nevertheless, an important risk variable for such violence is the presence of childhood sexual abuse of the woman.

In reviewing the literature, it becomes evident that women in the United States are more likely to be victimised through “assault, battery, rape or homicide by a current or former male partner than by all other assailants combined” (Council on Scientific Affairs 1992b, 3190–93). One in-depth study of one-on-one murder and non-negligent manslaughter cases across a five year period found that over half of all female victims were killed by male partners (Browne and Williams 1987).

The individual who is prone to violence often finds in his home ambience a ground that greatly facilitates his offensive conduct. The other members of the family, the victim or victims in this case, are often seen by the aggressor as “easy prey.” Indeed, the victim, even though partially able to express feelings of anger and frustrated by the mistreatment, is often unable or unwilling to report the violent behaviour due to ambivalent emotional feelings, rationalisations, practical economic factors, discomfort about disintegrating the family even further, the batterer’s repentance and begging for forgiveness, and last, but not least, because of a fear of retaliation. Indeed, “the risk of assault is greatest when a woman leaves or threatens to leave an abusive relationship,” and often the battered woman does not, in fact, leave the home (Browne and Williams 1987). Frank R. Scarpitti and Amie L. Nielsen write that “some wives, afraid to leave but unable to take any more abuse, may resort to killing their battering spouse, usually when he is vulnerable and weak, such as when he is sleeping” (1990, 311). In my experience with criminal offenders, the killing of the abuser often takes place in the kitchen where the woman impulsively and in self-defence reaches out for a kitchen knife as a weapon.

In those cases in which husbands are abused by wives, the wife's violent behaviour may be more frequent and more serious than the behaviour reported for husbands. However, Lenore Walker stated that the data indicates that women who kill their abusers resort to such violence as a last attempt to protect themselves from further physical and mental harm (1984). It has also been reported that 76% of a small sample of 38 women out of 50 who had killed their husbands had used the same weapon with which they had been threatened by him, each believing that the batterer was going to make good on his threat to use it against her (Walker 1989).

Some statistics report that when wives become aggressive within the marital relationship the rate of wife to husband assault is about the same as that of husband to wife (Davis 1998, 56; Straus 1996, 54). However, Davis questioned such statistics, reporting past FBI statistics showing that "in 1993 591 husbands and boyfriends died at the hands of their wives or girlfriends.... 1,531 wives and girlfriends died at the hands of their husbands or boyfriends," and that in 1995 (FBI report) "26% of female murder victims were killed by husbands or boyfriends.... [while] women or boyfriends killed 3% of male victims" (1999, 56). The innocent victims in such cases are the children who witness these parental homicides and are "emotionally traumatized, stigmatized, and deeply scarred by the terrifying event. They often exhibit debilitating symptoms comparable to those of post-traumatic stress disorder."[5]

Research on domestic violence has shown that half of all women will experience some form of violence from their partners during marriage, that more than one-third are battered repeatedly every year, and that women are six times more likely than men to be victims of violent crime in intimate relationships.[6] In 1991, more than ninety women were murdered every week. Nine out of ten were murdered by men.[7] Even though violence against women is more prevalent in the home, abusive husbands and lovers harass 74% of employed battered women at work, either in person or over the telephone, causing 20% to lose their jobs.[8] In 1997, there were 430 reported cases of homicide or negligent manslaughter in which the victim and victimiser were intimates (spouses, ex-spouses, boyfriends or girlfriends) (Maguire and Pastore 1999, 297).

Not even pregnancy protects women from abuse. Indeed, Walker stated that, "A disproportionately large number of women are assaulted while they are pregnant" (1989, 51). Another report stated that "[n]early 50% of abusive husbands batter their pregnant wives,"[9] while yet another stated that battered women are three times more likely to be injured while pregnant (Stark and Flitcraft 1985). A recent study from Italy found the 90% of battered women were subjected to physical and psychological violence even during pregnancy.[10] The consequences of battering a pregnant woman are not only physical pain, fright and/or despair, but at times miscarriage, rupture of the uterus, and precipitated labour, often with placental complications, low birth weight babies, and injury to or death of the fetus (Stark and Flitcraft 1985). Even though many battered women do not report the abuse to which they are subjected to the police, they frequently visit physicians because of their injuries and/or various other symptoms. Already in 1985, it was reported that battering accounted for one-fifth of all medical visits by women and one-third of all emergency room visits by women in the United States each year (Stark and Flitcraft

1985). The authors of that report stated that domestic violence was the largest single cause of injury among women seen in the emergency rooms and was more common than auto accidents, muggings, and rapes combined. In 1992, it was reported that, "between 22% and 35% of women presenting with complaints in emergency departments are suffering injuries or symptoms caused by ongoing abuse...[and] 25% of female emergency psychiatric patients are battered by a male partner; and up to 64% of female psychiatric patients are abused as adults" (Council on Scientific Affairs 1992b, 3191).

When the battering is severe, there are many physical symptoms that are reported and that require immediate medical attention. Typical injuries inflicted by an abusive person in cases of domestic violence are contusions and lacerations, usually of the head, face and neck, followed by those to the breasts or abdominal area. However, the symptomatology varies, and may consist only of vague physical complaints such as muscular or abdominal pains, headaches or difficulty with sleeping. Unfortunately, even physicians are not always able to recognise the disguised or masked battered-woman syndrome. Indeed, it is reported that "in only 8% of the cases in which explicit information about abuse (e.g., patient's statements about abuse) or very strong indications of abuse were recorded in the medical chart," were physicians able to discharge their patients with the correct diagnosis of spousal abuse (Council on Scientific Affairs 1992a).

When the battered victims or the victims of sexual abuse do call the police at the time of the offence or immediately afterward, in an attempt to stop the violence, they frequently do not follow through with the charges. Indeed, contrary to cases of stranger assault and stranger battery in which victims strongly pursue the aggressor, the victims of family violence often do not want to press charges, and when charges are instituted by the authorities they do not appear in court to testify. The case is then dropped. This seems to be a clear refusal of the mandatory (a.k.a. preferred) arrest law for family violence in effect in most of the United States since 1989 for the protection of the victim. Davis reported that in 1980 "many district attorneys [refused] to prosecute wife abuse on the premise that women would retract the charge to allow their husband to remain employed" (1999, 51; Pleck 1987). Today, however, many of the violent persons who act out against their spouses or other family members are unemployed and do not support financially their wives or children. Nevertheless, many women still refuse to press charges. How can this be explained? No doubt many are afraid, but it may be theorised that in many cases the victim's refusal to co-operate with any prosecution of the aggressive spouse or partner points out that the family struggle does not call for arrest but counselling. In other cases, reasons such as the victims' feelings of compassion and perhaps more objectivity once the aggression is over may be at the basis of the refusal to cooperate. It may be that in these cases they believe the violence was an interpersonal problem due to personality difficulties and socially problematic situations and that the batterers do not need incarceration but psychological help and assistance in redressing the deep and frustrating social problems (poverty, inadequate housing, unemployment, addiction) that are frequently precipitating factors in their violence.

The problem of battered women, who suffer the preponderance of domestic violence, is both puzzling and depressing. Statistics reveal the quandary in which these women find themselves. Already in 1975, one study reported that a high rate of separation between spouses (81%) was present among a group of one hundred battered wives (Gayford 1975). Although divorced and separated women compose only 7% of the population in the United States, one study found that they accounted for 75% of all battered women and report being battered fourteen times as often as women still living with their partners (Klaus and Rand 1992). Women who leave their batterers are at a 75% greater risk of being killed by the batterer than those who stay. To this effect, the application of the so-called restraining order (no contact with the victim) is very questionable. Indeed, the batterer at times becomes more hostile and vindictive and in many cases the restraining order may increase the likelihood of a future offence against the victim (Palermo 2004).

Physical abuse within a marital or co-habitational relationship leaves the victim with a profound sense of vulnerability, loss, betrayal, and feelings of severe hopelessness. These victims often become very depressed, and at times abandon their homes and become part of the large cohort of homeless people. Up to 50% of all homeless women and children in this country are fleeing domestic violence, but one study found that after finding temporary shelter, 31% of abused women in New York City returned to their batterers, primarily because they could not locate longer-term housing .[11]

Children and Adolescents. Those who are caught in the middle in a domestic violence situation are the children. The physical and sexual abuse of children and adolescents should be viewed as one of the worst criminal offences as it represents an act of violence perpetrated on a helpless individual, physically, emotionally and socially immature; an act of violence that unfortunately is all too common and that must not be ignored. Domestic abuse of children does not depend on the socio-economic level of the family. It is essentially the psychopathology and the unconventional attitudes of the abuser that are determining factors in the offence.

Infants and children are not new to physical abuse. In ancient societies they were not only frequently mistreated, but the infanticide of deformed or unwanted children was not an uncommon practice. During the reign of the Roman Emperor Justinian, in 529 A.D., special homes were established for children who had been abandoned or who had no parents. Throughout the centuries, very young children were used as cheap labour, and not until the 18th century was public opinion sensitised to the physical and psychological maltreatment incurred by these children. This brought about the institution of children’s homes as protective shelters. However, even there children were occasionally battered (Bastianon and De Benedetti-Gadini 1988).

Some researchers reported that the risk of child abuse is significantly higher when the partner is also assaulted (Hotaling and Straus 1989). Indeed, Walker wrote that nearly half of the men who abuse their female partners also abuse their children (1989). However, within the home, the mother is more often the batterer in the physical abuse of the child, probably due to the fact that she is more likely to be in contact with the child for long periods during the day. She may be frustrated by her inability to cope or by what she feels to be an impingement on her liberty. Gelles wrote that this is one of the few situations in which women and men are both likely to use a similar type of violence, finding that men and women are approximately equal in their disposition to use the most serious forms of violence on their children, including beating up, kicking, biting and punching and using guns or knives (Gelles 1978).

At times children are abducted by one of their parents and more than 50% of child abductions result from a situation of domestic violence.[12] Most of these abductions are perpetrated by fathers and their agents. Battering men use custodial access to the children as a tool to terrorise battered women or to retaliate for separation.[13] Abusive partners often use children as pawns in custody fights to coerce their female partners to reconcile with them. Often, these coercive incidents occur during court-ordered visitation.[14]

The abuse of children and adolescents, as with spouses, may be physical, sexual and/or psychological. Physical abuse may be comprised of a multitude of injuries that may be due to beating, punching, kicking, biting, burning and hitting. The neglect of a child or adolescent should be considered as an indirect form of abuse. Even shame, which is often used by parents in an attempt to discipline their children, can be considered a form of abuse. “The reason [shame is a punishment] is simple and perverse. The shame an autonomous person can arouse in subordinates is an implicit control” (Sennett 1980, 95).

C. Henry Kempe and colleagues first described the battered-child syndrome in 1962 and they reported that children battered physically by their parents numbered in the thousands each year. David Gil, in 1971, stated that there were at least 6,000 battered children yearly. Other studies in 1974 reported an approximate number of 200,000 to 500,000 cases of battered-child syndrome per year (Light 1974). In 1975, The National Center on Child Abuse and Neglect (NCCAN) of the United States reported 250,000 cases of physical abuse of children. However, in striking contrast to that number, a national survey of the American family conducted by Gelles reported that during the same year, 1,200,000 to 1,700,000 children in the United States had been battered by their parents, the battering consisting in being beaten, kicked or severely pinched (1978). Gelles also reported that from 460,000 to 750,000 children had been severely physically abused and 46,000 had been either threatened with, or struck with, guns or knives.

The original observations of child abuse by Kempe and his paediatric group gave a great deal of impetus to its detection, not only by paediatricians but also by emergency room personnel, visiting nurses, and social workers during home visitations. Kempe and colleagues concluded that 15% of children below the age of five had been maltreated, and in the 749 cases that came to their attention, the group of maltreated children reached a mortality rate of more than 10% (10.4%) (1962). Unfortunately, the actual number of cases of battered children was probably tenfold, and Kempe’s statistics may have been a gross underestimate of the actual number. Nonetheless, the report alerted public opinion to the problem of child abuse which, until then, had only been touched upon in some medical-legal literature such as the study by A. Tardieu in 1860 and that of Parristo and Caussade 1929. Prior to Kempe’s study, few people had suspected the frequency of maltreatment and physical abuse of children and of its consequences. In 1946, J. Caffey, however, had reported in his paper, “Multiple Fracture of the Long Bones of Infants Suffering from Chronic Subdural Hematoma,” that he suspected the cause of the above mentioned radiologically demonstrable lesions to have been due to physical abuse.

A national study on child neglect and abuse reported by the American Humane Association in the late 1970s had shown an escalation of abuse and negligence of minors from 33,546 reported cases of physical abuse of children in 1977 to 58,772 cases in 1979 (National Study on Child Neglect 1979, 81). By 1992, there were 2.9 million reported cases of child abuse and neglect in the United States. Of the reported cases, 27% involved physical abuse, 17% involved sexual abuse, 45% involved neglect, 7% involved emotional abuse, and 8% were classified as “other” which includes abandonment and dependency. In 1992, 1,261 children died from abuse – 37% as a result of physical neglect, 58% as a result of physical abuse.[15] Such violence is not limited to the United States and can be found throughout the world (Buris et al. 2000; Kaiser 1977; Kitamura et al. 1999; Scott 1977; Viano 1975). Indeed, “For over a decade, it has been recognised as an international epidemic,” wrote Robert Geffner (1997, 2).

When violence, especially sexual violence, is directed against children, there is, at times, a failure to properly recognise it because of the fact that it may be difficult to distinguish whether the parents were negligent or intentionally abusive. In addition, there is often a curtain of denial drawn by family members in cases of violence against children. They are often unwilling to accept the disclosures of their victimised children, or they attempt to protect one another from the possible consequences of these actions. And, because of their older age, adolescents are often unfairly perceived as being responsible for this maltreatment. Younger children, on the other hand, may have misconceptions about what sexual abuse is and may not reveal the abuse they have suffered. Also, children often deny being abused by their parents, possibly feeling that they provoked the abusive incident, and many abused children describe themselves as deserving it (Garbarino et al. 1986). This may be due to a deep need for the support and love which they fear would be lost if the abusive behaviour is reported, the fear of disrupting their parents’ relationship, or the fear of not being believed by other family members. So the child often suffers passively until the later part of the adolescent period when he or she may try to finally stand up to the offensive parent or to leave home.

As with other types of abuse, sexual abuse of children is not limited to any socio-economic group, but overcrowding in lower socio-economic classes where many children share a room and sleep together in one bed, or at times sleep in the same bed with their parents, may be conducive to incestuous relationships. At times such relationships may continue for years and stop only when the offending parent substitutes the grown-up victim with a younger sibling. This type of sexual abuse is a form of entrapment for children who, because of fear and threats, may become almost co-participants in one of the worst forms of exploitation of the child’s body and emotions.

The abuser in such cases is often the father or stepfather, but at times it may be other male figures in the household, such as brothers, uncles or family friends. One study, for example, found that most perpetrators of child abuse had been the fathers or father surrogates (62%), while abuse by other male family members was found to be relatively low (cousins or uncles [10.7%] and brothers [9.3%]) (Kendall-Tackett and Simon 1987). These results differed from those in David Finkelhor's earlier study, which had found that most perpetrators were brothers and male cousins, while fathers and father surrogates were a small percentage of the perpetrators (1979). It is possible that this can be explained by the use of different methods of data collection. In my professional experience, I have found that the sexual abuse of children or adolescent girls, and occasionally boys, has been perpetrated equally by fathers and step-fathers, who are often under the influence of alcohol at the time of the offence, which removes the last vestiges of any moral control.

In 1990, more than 208,000 youths between the ages of 12 and 17 "were reported to child protective service agencies as victims of abuse. These represented 25% of all cases reported" (Council on Scientific Affairs 1993, 1850). Adolescent girls are reported as victims more often than boys, especially in cases of sexual abuse. Except for sexual abuse the overall incidence of abuse and neglect in adolescents is similar to that in childhood and the injuries in older children are less serious than in the younger ones. This can be explained by the fact that the older child usually reacts to the aggressor, whoever it may be.

While boys younger than 12 years of age are reported to show higher rates of physical abuse than girls, the situation reverses itself when adolescent girls are compared to adolescent boys (Council of Scientific Affairs 1993, 1850). This may be due to the concern of parents for the consequences of the increasing autonomy of girls and/or their fear of the possible consequences of sexual misconduct. There also is a lower propensity for girls to engage in a defensive physical fight with a paternal figure such as might occur with adolescent boys who may engage in such conduct in order to ward off physical attacks.

In an attempt to understand the higher incidence of adolescent abuse and maltreatment, the growing surge of rebelliousness in the child entering the teens and into late adolescence must be taken into consideration. During that period, the adolescents may become oppositional or defiant. They may be involved in drug or alcohol experimentation or addiction. There is a struggle for independence and control and conflicts between duties and rights that often eventuates in a chaotic situation, which, even though temporary, may be destructive for family relationships. We are all well aware of the clash between parental dictates and the rebelliousness of these young people, and of the possibility that parents, especially fathers, feeling confused and angry, may try to exercise control of the child, at times some form of physical control. This is often felt by the adolescent to be abuse and he or she may rebel against the too-aggressive parent and move into an antisocial type of life, physically acting out against the parent and often running away from home. In fact, "incarcerated youths, homeless or runaway youths, and youths who victimise or assault parents have been shown to have high rates of prior maltreatment" (Council of Scientific Affairs 1993, 1850).

The traumatic experience of being battered or sexually abused is extremely disruptive for the normal development of the young victim. Its consequences involve the victim's physical, psychological, and spiritual self and also influence future interpersonal relationships. Nevertheless, in my professional experience I have seen many of these victims overcome the obsessive memories of their abused childhood and/or adolescence without developing any type of post-traumatic stress syndrome, and they have been able to enjoy life without fear and with realistic objectivity, depriving the haunting memory of the past of its negative powers.

As with spousal abuse, the majority of child abusers are persons with a particular personality makeup. They are usually dissatisfied with themselves; have a poor sexual identification; have a great deal of ambivalence towards the female figure stemming from a poor relationship with their mothers; are unable to relate properly to their wives or husbands; are shy, timid and fearful of rejection. They have often been battered by their father and frequently sexually molested. They suffer from feelings of jealousy toward their own children, especially those of the same sex, and have a fear of being supplanted by the children in their relationship with their spouse. Their battering and their sexual abuse are an unsuccessful attempt to assert their fragile identity.

Other Victims. Domestic violence is not restricted to women and children. In 1991 it was reported that approximately one out of every 25 elderly persons was victimised annually.[16] By 1998, there were almost 32,000 cases of victimisation of people 65 years and older (Maguire and Pastore 1999, 176). While that number is obviously not limited to cases of domestic violence, 51.1% of violent crimes are reported to have been perpetrated by non-strangers (Maguire and Pastore 1999, 179). At the beginning of 2000, it was estimated that "nine out of ten cases of elder abuse go unreported. Nationally, it was estimated that more than a half-million Americans aged 60 and older living at home have experienced abuse or neglect, including self-neglect" (Unknown 2000). An earlier report had found that of those who experience domestic elder abuse, 37% are physically abused. Of those who perpetrate domestic elder abuse, 30% are the adult children of the abused person.[17]

The infrequent but not-unknown victimisation of parents by their children must also be mentioned. Jerry Munder believes that when parents are "[b]ereft of [their function as] role models, they (men in particular)… submit to the sadism of the younger generation, whose socialization and moral development it should be their charge to encourage and direct" (1997, 31). I am not referring here to the unruly, uncivil behaviour of many young people towards their parents, or to young people's truancy, use of alcohol, drugs and participation in misdemeanant or felonious behaviour away from home (behaviour which obviously creates in parents anxiety, concern, depression, and the frequent disruption of the family's daily routine), but to the actual killing of parents by their children, usually during their adolescent period. Kathleen Heide wrote regarding the phenomenon of parricide that is not possible to ascertain the exact number of parents and stepparents slain by juveniles because of various data limitation. She found, however, that in one ten-year period [1977–1986] "as many as 65 natural parents – 45 fathers and 20 mothers – may have been killed by youths under 18" (1992, 4).

The killing of one's parents, father, mother, or both, represents the breakdown of one of the sacred taboos in the history of mankind. However, it is also as old as the history of mankind and writers such as Sophocles, Shakespeare and Dostoyevsky remind us of that in their writings. It was used by Freud, in *Totem and Taboo*, in his explanation of the origin of the Oedipal complex tendency, which he claimed is almost inborn in the developing child (1950). Adolescents who commit such crimes are usually sensitive, insecure, ambivalent, frightened and emotionally deprived. They have often sustained a great deal of physical, and at times sexual, abuse at the hands of their parents; there are reports, however, of children killing their parents only for financial gain.

As we justly castigate their parents' behaviour as unnatural and offensive, we should look upon the behaviour of these children in a similar way. We should not absolve the adolescent from the responsibility for similar crimes. There is no justification for *anyone* to abuse, victimise, or murder another person. By the age of 13, the majority of children, especially in present-day society, should have acquired a cognitive and moral stage of development adequate for social interaction, and only when suffering from a characterological disorder or psychotic condition do they at times lose their capacity to interact with others in a civil manner.

Psychiatric Illness. Psychiatric illnesses ranging from schizophrenia and bipolar illness to recurrent depression are occasionally at the basis of violent behaviour within the family, and the type and intensity of this behaviour may be of serious significance. In 1986, Roger Bland and Helene Orn reported a British study which, using detailed and specific definitions, found "annual rates of about 1/1,000 for severe abuse in children under four years old" (1986, 134). In their study they found that of the 1,200 persons considered, 2.6% of the parents admitted abusing a child. They found that a fairly high proportion of people exhibiting violent behaviour suffer from a psychiatric illness, and, more specifically, that the rate of violent behaviour of those with psychiatric diagnoses reached 54.4%. Bland and Orn claimed that particularly high rates for violence were found among people who were diagnosed as suffering from antisocial personality disorder and who also were addicted to alcohol, or among those who suffered from a recurrent depression with occasional suicidal attempts. In their statistics, the rate of depression combined with antisocial personality disorder and alcoholism reached 80 to 93% among those people exhibiting violent behaviour within the family.

Freud had pointed out that people with disorders of character whose psychopathology manifests itself in the form of abnormal destructive or life-threatening behaviour act out in their behaviour the fantasies that normal and neurotic people experience in their unconscious minds (such as in nightmares, or in the dreams of incest to which Plato refers) (Gilligan 1997). My experience, concurring with that of Bland and Orn, is that the occurrence of violent behaviour with serious consequences is perpetrated by people who can be classified as having a personality disorder of the antisocial type, who are addicted to illicit drugs and alcohol, and people with a paranoid delusional disorder.

In 1989, a study reporting the possible connection between head injury and marital aggression in offenders found that out of a group of 31 violent marital offenders, nineteen had a history of severe head injury. It also found that alcohol imbibition as reported by the offenders they studied, was present in slightly more than 48% (48.4%) of the sample (Rosenbaum and Hoge 1989). The possibility that damage to the frontal lobe structures of the aggressor might be at the basis of violent behaviour toward a spouse or others should be entertained. That the episodic dyscontrol syndrome due to organic factors may be at the basis of the violent behaviour is also a possibility; however, in my estimation it is somewhat rare. The dyscontrol is usually a reaction to eco-psychological stressors.

REFLECTIONS

Family violence should be a central issue of concern in every society, not only because of its immediate consequences to the primary victim – physical, sexual and even homicide – but because of the later psychological, domestic and social disruptions in the lives of all the members of the family, especially the children who frequently grow up with a fragile and dysfunctional psychological self. We can probably term some families "families of abuse." Indeed, the causes of physical and sexual abuse are not to be found only in the serious personal problems of the abuser, but also in a dysfunctional, chaotic family situation. Either extreme independence or excessive dependence is often present in members of this type of dysfunctional family, and both authoritarian families and overindulgent families may be abusive.

The drive for autonomy – the freedom of self-determination – seems to have been present since early in the history of humankind. The toddler, the child, and later the adolescent manifest this drive, which seems to be an intrinsic part of the developing person and is essential in the shaping of his or her character. However, since people do not live in a vacuum but in communities formed by families, within which one is in continuous contact with other members, whether parents, children, siblings, or grandparents, this impelling drive to self-determination finds it difficult to express itself completely. And since living together requires give and take for the smooth running of the family, there is a continuous rearrangement of the individual's own self-deterministic choices, and autonomy is necessarily curtailed. This should take place within limits, without infringing on the freedom for self-realisation of each member. That, at least, is what should happen within an *ideal* family, because autonomous choices must also take into consideration not only one's self but also others. It is expected that husbands and wives have their own personal convictions and that they try to convey them to each other. In doing so, they exercise their autonomous decisional capacity which, prior to externalisation to the other, they generally objectively appraise, exercising a certain degree of self-control that ideally takes into consideration the views and desires of their partner. In this situation, men "raised to value autonomy and competition as cardinal virtues...are expected to suspend their concerns in marriage in favour of intimacy and interdependence.... and [they] must exchange [their] dominance for emotional equality" (Campbell 1993, 104–5). However, for the man who is prone to violence, often due to past childhood experiences in a dysfunctional family, it is difficult to give up familiar and prejudicial ideas. He may be distrustful, may fear intimacy and feel that his weakness and inadequacy may be revealed if he gives in to his wife. Therefore, his possessiveness and fear drive him to assert his power and control over her. "The obvious certainty" says Davis, "is for most of human history men have been in charge of making family decisions. In our contemporary society, each of the cohabiting partners, because of many 20th century social changes, wants to predominate in the decision making process" (1999, 17).

The woman, on the one hand "socialized to exert internal control over...[her] anger" and, on the other, having recently acquired more independence and the right to self-realisation, is at first ambivalent about how to respond and may no longer be willing to assume a subordinate role in the household or to tolerate aggressive behaviour. (Campbell 1993, 115)Thus, she strongly reacts to the man's assertion of his dominance and both partners become inflexible in exercising their limited autonomy and their self-control; they clash with one another, they argue and fight, at times reaching the point of physical harm. Both partners face a disruptive confrontation, because they do not realise their interdependency, that autonomy is relative, and that life together requires compromise. Independent and dependent attitudes are two sides of the same coin and too much of either is not conducive to peaceful and happy cohabitation. The above reasoning applies as well to the relationship of parents with their children. However, in the latter type of relationship, parents must necessarily exercise an intelligent degree of control of their children's behaviour that is congruous with the child's emotional and developmental maturity.

At present, there seem to have been changes in the family give and take. Even admitting that the past was not as idyllic as people tend to remember, in too many families there is no longer the cohesion that was present then, through which mutual respect and concern for one another were the basis of the family's strength. This may be in part the consequence of unbridled individualism and pragmatism and of individual rights not contained within the limits of common sense. One may ask what this has to do with domestic violence? It is my belief that the social repercussions of extreme individualism and pragmatism are often felt at the level of the human family in a negative way. This way of life in a highly technological era has almost automated people and has disturbed the family balance. It has created a double role for women/mothers. Their present-day role in the workforce takes time from their families and emphasises, at both a conscious and subconscious level, a subtle competitive stance with the husband, and it confuses their roles. They become deeply involved with their jobs, because the work organisation outside of the home requires intense application and teamwork. But that co-operation is often not carried over into the home. We are then faced with a new type of family in which spouses are often quasi-independent from one another, resentful of and angry about each other's autonomy. Misunderstandings at an interpersonal level develop among all family members, bringing about dysfunctional relationships that often lead to maltreatment and abuse with tragic consequences.

Excessive autonomy on the part of spouses and partners has contributed to a high level of physical violence and divorce, and it has facilitated the tendency to easily accept the one-parent family. On the part of children and adolescents it has led to conduct problems and defiant behaviour toward parents. Fathers who are uninvolved with family life lose their functions as role models, and a vicious cycle of disinterest, rejection, hostility, aggression and violence ensues. Sex is used with a demeaning controlling purpose and not as a purveyor of love and attention. As a result, rape, incest and sexual assault may occur.

The Supreme Court of Mississippi, in 1824, followed by Maryland, Massachusetts, and North Carolina, decided that a husband has the right to use moderate physical chastisement towards his wife (Asmus et al. 1991). However, since 1920, all states have rejected the above legal decision. Nonetheless, even though a completely different legal point of view exists today, the spousal abuse continues in the United States, possibly due to deeply rooted and antiquated socio-cultural ideas on the part of the male sex. The quest for power and control is a major motivating factor behind the aggressiveness of a batterer, who, deeply inadequate, shows a facade of superiority and a controlling attitude. There is still a certain reluctance on the part of the police, the judicial system, and even of the population at large, to interfere with any marital discord. Nevertheless, domestic violence is part of a multifaceted relationship, and the relationship between the batterer and the victim, often of a sado-masochistic type, is important from a community point of view because of its social and economic consequences.

It is natural to ask why either the wife or the husband submits to the violent behaviour of which they are victims. In addition to variables such as the physical fear of retaliation, complete economic dependency, desire to keep the family together, it may be suggested that in some cases the battered partners realise that the batterers, towards whom they may have ambivalent feelings, is a person who basically may act in a such an unacceptable way because of his or her psychopathology. In other words, the victims see the victimisers as being mentally disturbed and tend to justify their behaviour to the point of considering them to be victims as well.

One can appreciate the complexity of the problem of domestic violence, not only because of the sado-masochistic relationship which is often a part of this type of violence, but also because the persons involved, frequently husband and wife, bring into their relationship their own life experiences prior to their marriage. In family violence, the microcosmal family group seems to deal with the same issues that are debated in society – economic decisions, human relationships, decision making, values and options, trust, autonomy and self-realisation, fear, control, responsibility and irresponsibility. With the exception of those rare cases of obvious mental illness in some abusers, domestic violence is basically a sociological problem, and the victims and victimisers may be the unfortunate actors/reactors in the eternal drama of life which, especially during periods of social transition, may result in tragedy.

NOTES

1. L.W. King, translator, *Exploring Ancient World Cultures. Hammurabi's Code of Laws*. Http://eawc.evansville.edu/anthology/hammurabi.htm, 10/3/97, 1–22.
2. Fulgham v. State, 46 Ala. 146–147.
3. National Coalition Against Domestic Abuse. NCADV Fact Sheet. Denver, 1994.
4. *Webster's Ninth New Collegiate Dictionary* (Springfield, MS: Merriam-Webster, 1988).
5. S. Burman and P. Allen-Meares, *Neglected Victims of Murder: Children's Witness to Parental Homicide*, National Association of Social Workers, Inc. (1994) CCC Code: 0037-8046/94.
6. *NCADV Fact Sheet*
7. Senate Judiciary Committee Report. *Violence Against Women: A Week in the Life of America*, October, 1992.
8. *NCADV Fact Sheet*
9. U.S. Senate, Committee on the Judiciary, Ten Facts on Women and Violence, *Hearings on Women and Violence*, August 29 and December 11, 1990, 78.
10. La gravidanza non ferma la violenza sulle donne. (Pregnancy does not stop violence against women.) *La Repubblica*. April 9, 2000, Cronaca.
11. *NCADV Fact Sheet*
12. Ibid.

13. Ibid.
14. Ibid.
15. Ibid.
16. Ibid.
17. Ibid.

REFERENCES

Arnaud-Duc, N. (1995) The law's contradictions. In G. Duby and M. Perrot (Eds.), *A History of Women: Emerging Feminism from Revolution to World War*, Vol. IV. Belknap Press of Harvard University Press, Cambridge, MS/London.

Asmus, M.E., Ritmeester, T. and Pence, E.L. (1991) Prosecuting domestic abuse cases in Duluth: Developing effective prosecution strategies from understanding the dynamics of abusive relationships. *Hamlin Law Review* 15, 115–66.

Barri-Flowers, R. (1996) The problem of domestic violence is widespread. In K.L. Swisher (Ed.), *Domestic Violence*. Greenhaven Press, San Diego.

Bastianon, V. and De Benedetti-Gadini, R. (1988) Abuso e incuria verso l'infanzia (Abuse and maltreatment of infants. In F. Ferracuti (Ed.), *Tratto de Criminologia, Medicina Criminologica e Psichiatria Forense (Treaties on Criminology, Criminological Medicine, and Forensic Psychiatry*. Giuffrè, Milan: pp. 165–88.

Bland, R. and Orn, H. (1986) Family violence and psychiatric disorder. *Canadian Journal of Psychiatry* 31, 129–37.

Browne, A. and Williams, K. (1987) *Resource Availability for Women at Risk: Its Relationship to Rates of Female-Perpetrated Homicide*. Presented at the American Society of Criminology, Montreal, Quebec, November 1987.

Buris, L.F., Posta, J., Buris, L., et al. (2000) Battered children, medical forensic aspects: A twenty-year review from Eastern Hungary (1963–1982). *International Journal of Offender Therapy and Comparative Criminology,* 44, 657–66.

Caffey, J. (1946) Multiple fractures in the long bones of infants suffering from chronic subdural hematoma. *American Journal of Roentgenology* 56, 163.

Campbell, A. (1993) *Men, Women and Aggression*. Basic Books/Harper Collins.

Council on Scientific Affairs, AMA. (1992a) Violence against women: Relevance for medical practitioners. *JAMA* 267, 3184–9.

_____. (1992b) Physicians and domestic violence: Ethical considerations. *JAMA* 267, 3190–3.

_____. (1993) Adolescents as victims of family violence. *JAMA* 270, 1850–6.

Davis, R.L. (1998) *Domestic Violence*. Praeger, Westport, CT.

Donziger, S.R. (Ed.) (1996) *The Real War on Crime: The Report of the National Criminal Justice Commission*. Harper Perennial, New York.

Finkelhor, D. (1979) *Sexually Victimized Children*. Free Press, New York.

Fitch, F.J. and Papantonio, A. (1983) Men who batter: Some pertinent characteristics. *Journal of Nervous and Mental Disorders* 171, 190–2.

Freud, S. (1950) *Totem and Taboo*. Tr. J. Strachey. Norton, New York.

Garbarino, J., Shellenback, C. and Sibis, J. (1986) *Troubled Youth, Troubled Families: Understanding Families at Risk for Adolescent Maltreatment*. Aldine Company, New York.

Geffner, R. (1997) Family violence: Current issues, interventions and research. *Journal of Aggression Maltreatment and Trauma* 1, 1–25.

Gelles, R.J. (1978) Violence toward children in the United States. *American Journal of Orthopsychiatry* 48, 580–92.

Gelles, R.J. and Cornell, C.P. (1990) *Intimate Violence in Families*, 2nd Ed. Sage, Newbury Park.

Gayford, J.J. (1975) Wife battering: A preliminary survey of One Hundred Cases. *BMJ* 1, 194–7.

Gil, D.G. (1971) Violence against children. *Journal of Marriage and the Family* 33, 637–48.

Gilligan, J. (1997) *Violence*. Vintage Books, New York.

Gregor, J. (1990) Male dominance and sexual coercion. In J.W. Stigler, R.A. Schweder and G. Herdt (Eds.), *Cultural Psychology*. Cambridge University Press, Cambridge/New York/Melbourne: 477–95.

Heide, K.M. (1992) *Why Kids Kill Parents*. Ohio State University Press, Columbus, Ohio.

Hotaling, G.T. and Straus, M.A. (1989) Intrafamily violence and crime, and violence outside the family. In L. Ohlin and M. Tonry (Eds.), *Family Violence*. University of Chicago Press, Chicago: 315–76.

Kaiser, G. (1977) Child abuse in West Germany. *Victimology: An International Journal* 2, 294–306.

Kempe, C.H., Silverman, F.N., Steele, B.F., et al. (1962) The battered child syndrome. *JAMA* 181, 17–24.

Kendall-Tackett, K.A. and Simon, A.F. (1987) Perpetrators and their acts: Data from 365 adults molested as children. *Child Abuse and Neglect* 11, 237–45.

Kitamura, T., Kijima, N., Iwata, N., et al. (1999) Frequencies of child abuse in Japan: Hidden but prevalent crime behind the door. *International Journal of Offender Therapy and Comparative Criminology* 43, 8–20.

Klaus, P. and Rand, M. (1992) *Special Report, Family Violence*. Bureau of Justice, Washington, DC.

Lansky, M.R. (1993) The family genesis of aggression. *Psychiatric Annals* 23, 494–9.

Light, R. (1974) Abused and neglected children in America: A study of alternative policies. *Harvard Educational Review* 43, 556–98.

Maguire, K. and Pastore, A.L. (Eds.) (1999) *Sourcebook of Criminal Justice Statistics 1998*. U.S. Dept. Of Justice, Bureau of Justice Statistics, Washington, DC.

Munder, J.R. (1997) *Sadomasochism of Everyday Life*. Simon and Schuster, New York.

National Study on Child Neglect and Abuse Reporting (1979) American Human Society. Reports of abuse or neglect of minors in 33 jurisdictions. *Sourcebook of Criminal Justice Statistics*. Government Printing Office, Washington, DC.

Palermo, G.B. (2004) *The Faces of Violence*, 2nd Ed.. Charles C. Thomas, Springfield, IL.

Parristo, P. and Caussade, L. (1929) Les sérvices envers les enfants. (Infant Abuser). *Annales de Médecine Légale (Annals of Legal Medicine)* 9, 398.

Pittman, D.J. and Handy, W. (1964) Patterns in criminal aggravated assault. *Journal of Criminal Law, Criminology and Police Science* 55, 1242–5.

Pleck, E. (1987) Criminal approaches to family violence. In L. Ohlin and M. Tonry (Eds.), *Family Violence*, Vol. 2. *Crime and Justice*. University of Chicago Press, Chicago: pp. 1640–1980.

Rosenbaum, A. and Hoge, S. (1989) Head injury and marital aggression. *American Journal of Psychiatry* 146, 1041–51.

Scarpitti, F.R. and Nielsen, A.L. (1990) *Crime and Criminals*. Roxbury, Los Angeles.

Scott, P.D. (1977) Non-accidental injury to children. *British Journal of Psychiatry* 131, 366–80.

Sennett, R. (1980) *Authority*. W.W. Norton, New York/London.

Stark, E. and Flitcraft, A. (1985) Child abuse and social heredity: What is the relationship? In N. Johnson (Ed.), *Marital Violence, Sociological Review Monograph*, #31. Rutledge and Kegan Paul, London.

Stein, D. (1993) *The Woman's Spirituality Book*. Liewelly Publications, St. Paul, MN.

Straus, M.A. (1996) Domestic violence is a problem for men. In K.L. Swisher (Ed.), *Domestic Violence*. Greenhaven Press, San Diego.

Straus, M.A., Gelles, R.J. and Steinmetz, S.K. (1980) *Behind Closed Doors: Violence in the American Family*. Anchor Press/Doubleday, Garden City, NY.

Tardieu, A. (1860) Etude médico-légale sur les sérvices et les mauvais traitements excercès sur les enfants. (A medico-legal study on the abuse and maltreatment of infants.). *Annales de Hygiène Légale (Annals of Legal Hygiene* 13, 361.

Thornhill, R. and Palmer, C.T. (2000) *A Natural History of Rape*. The MIT Press, Cambridge, MA/London.

Unknown (2000) Elderly also need protection. *Milwaukee Journal Sentinel* April 11, 14A.

Viano, E.C. (1975) The battered child: A review of study and research in the area of child abuse. In I. Drapkin and E. Viano (Eds.), *Victimology: A New Focus*. Health, Lexington: 145–64.

Walker, L. (1984) *The Battered Woman Syndrome*. Springer, New York.

_____. (1989) *Terrifying Love: Why Battered Women Kill and How Society Responds*. Harper and Row, New York.

Wolfgang, M. (1958) *Patterns in Criminal Homicide*. University of Pennsylvania Press, Philadelphia.

DAVID N. WEISSTUB

CHAPTER 11
BALANCING AUTONOMY AND TRADITIONAL VALUES IN TREATING TERMINALLY ILL PATIENTS: TOWARDS LOCATING THE RIGHT QUESTIONS FOR JAPAN

It is frustrating both for Eastern and Western observers to discern with any exactitude points of similarity and dissimilarity in approaching questions of fundamental values within their respective cultures. This is so for a number of reasons. The interacting parties are oftentimes a self-selected group of professionals, who, by virtue of having spent considerable time in professional work and friendship in either culture, despite the desire to be mutually respectful, end up in a state of sincere confusion. Professionals, after all, share not only vocabularies, but also have found themselves in practical situations where appeals to historic values or tomes of abstract philosophy appear far fetched in the circumstances.

In the internet era, where thought is immediately accessible for a globalized community, professionals who do not live primarily in the abstract world of philosophical simplification, prefer to deal with each other on the basis of the here-and-now, wanting more to hear the narratives of their patients' universes and subjective feelings than to approach hard choices from the point of view of derivational logics which deduce from a set of metaphysical presuppositions about how these first principles could lead to different and/or just results.

Nevertheless, we insist that there is virtue in two pursuits: first, attempts to clarify how philosophical traditions have impacted on cultural thinking, including communities of professionals and secondly, in the interest of anthropological sensitivity, to articulate how customs and mores are apt to influence our judgment on matters of such urgency as life and death related medical decisions.

However well-intended our approaches to the aforementioned might be, the paths are fraught with either culturally driven prejudices or ideological commitments, sometimes unarticulated or even unconscious. Curiously enough, experts are often susceptible to forms of subtle prejudice without even realizing how a partial knowledge of a culture can distort perception. For example, on the End-of-Life question, a North American scholar recently argued that suicide had an essentially different role in the cultural history and even contemporary thinking in Japan in comparison with Western societies (Young, 2002). The distinction was drawn between classical Japanese life during the Edo period where the role of the Samurai was central, in contrast to later Western influences which came to prevail

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 143–152.

on Japanese public psychology, including that of the social and professional elites during the Meiji epoch. Such a line of argument was logically connected to the kamikaze phenomenon in the Second World War. Altogether the argument was plainly put. Japanese society is oriented to notions of duty, public solidarity and communal identification in sharp distinction from Western societies which employ an asymmetrical set of commitments to individualism, contractual thinking, and existential self-fulfilment at the expense of such hallowed Japanese institutions as the family, and immediate extended social structures, such as one's workplace.

It is not difficult to stretch the logic of such opposing world views into seeing how laws and professional attitudes towards life take shape. If the deduction is made that individual life counts for less in Japan, for example, than in the West, a leap of judgment has been made which, in my view, should be treated with the utmost caution. Modern transformations of the Japanese family have come into full force while the need for family and even extended family has equally come to the fore not only in the Neo-Conservative movements in the West, but also in the values that have surfaced between generations. The philosophical position of existentialism and the experimentalism of the 1960s, which translated into radical Libertarianism, have been replaced by a battle of values where reverberations towards more traditional social structures have become the dominant theme. In parallel, in Japan we can observe deep-felt reactions against and around issues of paternalism which have resulted in women, youth and pace-makers, within Japanese culture calling for a redefinition of attitudes where personal fulfilment has now become noticeable in trumping various fidelities to the past (Higuchi, 1992). Whereas Japan has been moving with some rapidity towards a version of Western modalities, equally the West has seen the pendulum swinging in the direction of more classical or tradition-bound social constructions.

The complexities of 21st century life have displaced the easy-at-hand anthropological observations that depict the respective cultures. On the other hand, in going beyond these well-known distinctions it is imperative that we avoid conflating the two universes based on an acknowledged globalism. Anthropological sensitivity requires that we look carefully at the difference between deep structural and superficial entries into these cultures. Even if we do not represent these cultures as being in a period of rapid transformation, we must be vigilant in observing where public attitudes are changing, and whether these are attached to gender, class differentiation, age variables, minority vs. majority status, exposure to international training in other cultures, language facility, and joint professional projects of a trans-national nature. Without viewing cultures in such intricacy, we are bound to fall into error in making misleading generalizations. The challenge should be to explain subtle differences rather than making broad generalizations of limited utility due to the shortcomings of abstracting away from the real cases. Any cross-cultural comparisons should be done with the observation that historical differences are highly relevant but that narrative in context, to be understood properly, should be viewed as multifaceted.

In medical ethics there are archetypal images that signify the tendency of even experts to read self-fulfilling scenarios into our professional record keeping. In dealing with revelations of a Cancer diagnosis, Westerners rapidly conjure up the image of a Japanese doctor solemnly addressing a family behind a screen where even an educated patient is lured into wilful blindness. The patient is depicted in such imagery as passive and almost childlike while the doctor is perceived as autocratic and ominous and in a collusion of maturity and good-judgment with the family, possessed of all of their faculties and whose love for the patient is intact and uncompromised. Although critical minds of the contemporary Japanese situation might view this as a parody of what actually goes on, such archetypes suit the needs of the Westerner's subtle prejudice, namely to feel superior in the face of the depiction of patient passivity.

From another point of view, enlightened Japanese thinkers might have the tendency to modify only mildly this portrayal, believing that the model overall sustains a Japanese social structure well worth preserving (Ishiwata and Sakai, 1994).In the opposite direction, Japanese observers, even those who have worked for prolonged periods in Western societies, frequently come to the conclusion that the Western model, and especially its North American form, fuelled by egalitarianism, the rhetoric of informed consent, and an overemphasis on me-ism results in a kind of social bedlam where individuals proclaim their empty rights, while stripped of family support and benevolent caregivers, within health systems where there is no universal commitment to State assistance. In both cases of East and West, commentators are ready to point out that these archetypal images do not reference properly the intricacies of real cases.

In the Japanese context, ready data can be found to reveal that the tension points between individuals, their families and the health professionals can be dissected into smaller universes or narratives where there are indeed many levels of frustration and ambivalence, not only with respect to the social structures themselves, but as well on how decisions should be consulted about and at what point in the trajectory of illness (Hayashi et al. 2000) (Long, 2002). Equally, Westerners will be quick to defend themselves when under cultural attack to point out that most citizens have some form of social support of a highly relevant nature and that there is great resistance against the depersonalized nature of health delivery and the affording of universal health care. In any event, many Western societies, due to their great social diversity, contain traditional patterns of family life. Furthermore in many socialist minded political cultures there are longstanding universal health care systems. Finally, in the heterogeneous health professional communities of many countries in the West, there is an abundance of foreign-trained health care professionals whose origins are so-called traditional societies. This is perhaps most pronounced in the nursing and social worker professions where shortages have required importation of foreign-trained professionals from developing economies.

The more pressing reality is that there are a multitude of interactions, both in theory and practice, between North American and Japanese health professional cultures. The world of bioethics has already produced an international vocabulary (Macer, 1993). But here the problem is one of imperial dominance. To what extent have philosophical traditions been superimposed such that the translation impact is confused (Tanida, 1996)? On practical issues international trends have been taken up so quickly that even statistical information can be subject to distortion or rapid transformation, reflecting the impacts of public lectures, reading materials, and generationally oriented attitudes that are reshaped according to fashion.

It is difficult to assess within these processes of globalization, how much of the 'ancient' remains in both the public or high-culture psyches, and the degree to which there is a shared universe even among professionals, in fighting for the preservation of national codes and customs (Weisstub, 1998). Among young professionals in medical or law faculties, how many of these individuals actually know the primary names of leaders in Utilitarian or Deontological philosophies, let alone the contents of the actual philosophies of Mill or Kant. In similar terms, to what extent do even the proclaimers of the uniqueness of Japanese philosophies know the proper origins of thought influencing medical ethics from the perspectives of the Confucian and the Shinto traditions.

The watering down effect of technological cultures in the East and West is such that the connectors between first principles and practical decision-making are, in most cases, highly elusive (Weisstub, 1998). There is a tendency to assert mantras of cultural residues, shadows from the past that protect our sense of 'cultural-self' rather than addressing how, in real terms, abstract philosophies of a distinctive nature have clear impacts on how we think and decide. If we are correct in this observation, then it may be a more worthwhile pursuit to think about how certain basic principles should guide all liberal-minded progressive cultures which can agree upon a modicum of respect for 'self', while admitting the importance of the extended circles of support and care. In so doing, it may emerge that the real differences lie at the periphery rather than at the core (Lambris, 2003).

Let us now turn to reflect upon a number of core concepts to include autonomy, dignity and vulnerability. At the heart of the East/West dichotomization is the postulated subtext of two world views: The one feudal, the other democratic. The etymological origins of 'autonomy' in the Greek city state, where self governance based on laws was the unifying instrument of this legacy, have prompted modern Western philosophy to see a silver lining running from the Periclean democracy to the individualism of the Kantian enlightenment (Dworkin, 1998). Libertarians in the West have regarded any alternative to this 'individual' based concept of democratic life in decision making as a regression to the feudal norm where the idea of a contracting individual negotiating her way through the social order remains alien. In this way, Japanese scholars, educated in the philosophies of the Western enlightenment have wished to subtly address the lack of respect for the individual to be found in the culture (Hoshino, 1995). Apologists or defenders of Japanese culture have pointed out the uniqueness of Japanese humanism which, borrowing from the enlightenment of balance and harmony in a tradition stretching from Confucius, bring calm and respect to all parties who function in a mutually supportive structure of interdependency. In this way, autonomy would not be regarded as alien necessarily, but a superfluous concept which adds nothing to the love and respect already experienced in a well lubricated social whole (Glick, 1997).

Towards an Integration of East and West If autonomy simply translates itself into a broad concept of respect for humanity and the uniqueness of each human life, the two universes as described should not be regarded as mutually exclusive. That is, from a classical Japanese perspective limiting one's self in order to achieve harmony with nature or others, and acknowledging mentorship, superiority, leadership, parentalism, etc. need not be reduced to a denial of one's self but the recognition that the fulfilment of self may only be appreciated through the recognition of the other and the need to receive support and love in order to be a proper self (Smith, 1986). From this vantage point, Eastern critics view the classically explained Western 'self' as a subject possessed of a vapid liberty. It is a corollary of this that rights attached to the self expressed outside of a social context are viewed as having misshapen moral meaning. From this point of view the notion of autonomy may only be given a richness of meaning when the relationship between autonomy and a broader set of fundamental values is properly understood (Rendtorff, 2006) (Pellegrino, 1992).

Dignity as a value should be seen as intrinsic from the humanistic point of view and as a logical pre-condition to the achievement of autonomy regardless of cultural context (Weisstub and Thomasma, 2001). In this way the humanist basis for East and West can be unified and properly described.

Human dignity, more than any other concept, has proven itself a convergence point for a humanistic orientation in bioethics. This idea, connected to Kant, but protected by philosophers of highly variant schools of thought, presents humanity as connected to participation in a human community with no price attached to it. It is this that lies at the center of universal ethics. The notion of intrinsic dignity is helpful to understand what is at play. Dignity, for example in the medical context, is connected to the very notion of personhood and is attached to human beliefs, unconnected to admiration, social standing, education, intelligence or any set of special skills or powers. It is the human value by virtue of being human and is prior to the power or process of attribution by any other human being. In Kant's classic statement "Humanity itself is a dignity". What flows from this, in terms of dignity, is a demand for respect.

As an idealized first right, human dignity is as suitable as any other concept to fuel both our medical and judicial systems with appropriate respect for persons. However, the question persists whether apart from an idealized statement which proclaims our respect for personhood, there is a logic for decision making that directs our judgment to conclusions where there are conflicting values. Is human dignity best articulated through a consensus morality? Can it only be articulated over a long process of amalgamating other rights, values, principles and rules, enunciated through laws and legislation (Thomasma, 1997)? What does the concept of human dignity impart to us more that we might see cynically as political necessity or idealization?

The key might lie in connecting human dignity to the notion of vulnerability. Herein lies the grounding and testing of human dignity (Goodin, 1985). Our testament of human dignity is revealed in cases of death and dying and our handling of vulnerable populations such as the elderly. In liberal democratic societies it is in the proportionality of how one actualizes respect for persons in the face of social and economic pressures that human dignity is given meaning.

There are deep psychological needs with respect to dignity that transcend cultures. In that sense we might see the notion of honor even preceding the value of dignity (Weisstub, 2002). The psychological need for being honored is timeless. It is neither feudal nor a child of the enlightenment, nor modern in the sense in which persons locate their own self worth through principles such as equality or a notion of the authentic self (Sulmasy, 2006). This notion of being honored precedes modern concepts of dignity insofar as it addresses the impulse of the handicapped and the vulnerable to be properly regarded. This is less abstract than the philosophical language of human dignity and its legal encapsulations. In fact, when dignity is taken away from a rights vocabulary, and is channelled into a language of charity and benevolence, it may thus be best understood as coming close to the notion of honor as an existential precondition for the elevation of the medically vulnerable. Ultimately, we should observe that honor and dignity have an interchangeable vocabulary of respect, concern and even mutuality. If so, then the choice of words should by this fact recede as a matter of importance and give way to the more pressing question of how to concretely protect vulnerable populations.

The challenge for the respective cultures of East and West is, having admitted a shared universe of respect for humanity, explained in the name of human dignity, and in the face of all humans sharing a finitude of vulnerability, to see how we can actualize respect for human subjects (Macklin, 1999) (Japan Geriatrics Society. 2004).

We might observe in dealing with the terminally ill that neither the established principles which dominate bioethics such as beneficence, nor legal remedies such as informed consent, have been proven to be of practical use in resolving hard cases. Alas, these principles and legal remedies to which we have subscribed in divergent social cultures, have not translated into effective remedies or univocal resolutions. It should be readily admitted that the most generalized moral principles have little predictive value. Furthermore, insofar as the application of legal principles such as informed consent has resulted in autonomous actions causing harm to individuals and their families, principles of law have become the subject of disquiet among caring professionals. Legal remedies are highly selective and irregular and do not often result in protecting the special populations for which such doctrines were initially directed.

The best we can probably accomplish is to develop techniques for achieving empathy among health care professionals (Loewy, 1991) (Weisstub, 2004).

Vulnerable Populations. As an introduction to reflecting on the terminally ill population it is interesting to explore two parallel realities in Japan. There is an exponentially increasing aged population requiring special services. Equally, Japan is saddled with a dramatically higher level of institutionalized mentally ill persons to be found anywhere in the industrialized world. Within the latter category, there are a number of anomalies and variables which are highly distinctive (Weisstub and Carney, 2006). The vast majority of institutionalized mentally ill patients are housed in for-profit institutions creating special economic pressures. The deeper reason however for the large number of institutionalized patients directs us more towards deep structural characteristics of Japanese society (Weisstub and Arboleda-Florez, 2000). The sympathetic interpretation of the data is that this occurred because of the family structure being so accentuated that is was necessary for the hospital authorities, under the broad rubric of state sustenance, to take over responsibility. Sympathetic interpretation accentuates a morality of care and distinguishes the Japanese situation from the policies of abandonment due to fiscal constraints and libertarian philosophies which have contributed in Western countries to homelessness and the criminalization of the mentally ill. Unsympathetic commentary would point out that Japan, being a hierarchical and perfectionist society, marginalized and denigrated persons regarded as defective or lacking in social utility. Because families were profoundly stigmatized by having such members among them in a shame oriented culture it was a natural consequence to see the mentally ill warehoused in conditions not dissimilar from the large asylums produced in Western societies in the industrial era. There is in fact a very low ratio of care for the mentally ill populations compared to other areas of medical treatment in Japan (Weisstub, 2003).

In order to have a clear view of how the situation is likely to unfold in terms of the terminally ill aged population it is important that we acquire a thorough understanding of public attitudes towards the aged, and project the effects of government restraints in future funding. Without responding to these variables any set of guidelines or ethics will fall short of expected targets of care. As well, it is critical that there be an assessment of attitudes towards the terminally ill population with respect to their potential assertion of rights and demands on the system not only from the point of view of the family in transition but as well from the perspective of health professionals at every stage of their careers and position within the existing and potential hierarchies of medically related decision making (Mogi, 2003). If it is true that a Japanese version of Western individualism is rearing its head, particularly among the youth, it would be blind-sighted to avoid calculating the weight of changing social patterns on consumer demands against existing paternalistic structures. Tendencies in Japanese culture in the direction of patient consumerism, which can be seem as a reaction against a patriarchal state and familial authority, will over time likely contribute to an aging population making its defense of rights and entitlements against resistant forces from within the family and the State.

Concurrent with increased recognition of individuals asserting their rights to health, indeed prolongation of life using advanced technological means, there will be greater pressure on the state to deplete and prioritize resources. To what extent is it realistic in Japanese society that terminally ill persons' rights be connected to an intrinsic right to human dignity? If health is understood as a resource, then it will be deemed improper to view claims for health among the population as absolute. Rather, health will be contemplated as a stipulated right, one which can be attributed or denied depending upon the limitations of the public purse (Sulmasy, 2006). This is how, in the American system, human rights are celebrated at the expense of medical protection. This is not the view held in societies with unbound resources who have committed themselves to a universal declaration of entitlement. Certain welfaristic liberal societies such as Sweden, Holland and Canada have made such claims. However, close scrutiny of these cultures reveals that they are now in turmoil with respect to health rights and are having endless social debates which are highlighted in current political elections.

The right of the terminally ill to end life, expressed as a human right, is different from the right to expect high cost treatments or palliative care offered in optimum circumstances. Among the panoply of claims of group rights, state and religious interventions, and the assertions of families there is not only diversity about presuppositions about fundamental principles, but also lobbying interests that will vigorously unfold.

In the context of these conflicts there is merit in raising a series of questions in order to firstly lay out the definitional issues relating to the terminally ill aged population.

1. What differences are there in Japan in theory and practice between institutionalization, instances of multi diagnosis, or compromised living arrangements such as group homes or assisted living?
2. Is there a crisis with respect to the terminally ill in Japan or just a perceived crisis based on Western perceptions of translated concepts from foreign sources? Should we view these influences as having a distorting effect on Japanese culture?

Secondly it is imperative that the theoretical foundations be explored about the grounding of Japanese values in order to gain a proper understanding of differences in approach between Eastern and Western perspectives.

1. Within the newly emerging communities of Japanese bioethicists, can we differentiate a Japanese orientation from a Western approach? How can we designate these differences in theoretical terms?
2. In live situations, is it clear that these different approaches, if they do exist, determine divergent outcomes or does practical experience dictate that the subjectivity of the circumstances make little difference in periods of crisis decision making.
3. Is it realistic to turn back to ancient texts and approaches to health that are no longer mainstream, or particularly evident within the frameworks of technologized medicine?
4. Are there modalities of conflict resolution endemic to Japan that could be employed to cope with inevitable conflicts?

Thirdly, the cultural variables that are claimed to be meaningful variables in interpreting and applying assessment, treatment and policies for Japanese elderly must be given in depth attention.

1. Are there specific culturally sensitive means to educate medical practitioners, students and families to increase sensitivity toward the elderly?
2. When conflicts arise within families in Japan on how to treat the elderly, which parties or frameworks of decision making are best suited to the culture?
3. What is the equivalent in Japan of alternative medicine found in North America and Western Europe? Does this convey a set of values and attitudes in the culture different from such modalities found in the West?
4. What are the countervailing forces to the importation of Western legal approaches as devices to cope with claims about the right to die and the right to health?

Fourthly the central concept of competency has to be appreciated in its particularities within the legal system of Japan and its special applications.

1. Is the approach to competency with regard to the terminally ill elderly different in Japan to other countries? If so, to what extent have health professionals become sensitive to these realities?
2. What level of competency should be addressed and respected as a condition for resisting family demands when found in opposition? Are there particularities in Japan with respect to the use of living wills?
3. What level of formality for adjudicating differences is commonsensical given current Japanese social realities?

Fifthly a number of policy challenges have to be addressed at the planning level where linkages should be made with the prior questions noted here.

1. Is it a potential problem that changing attitudes will reverse the old adage of Japan as a society of respect for elders such that elders are likely, over the next few decades, to become an embattled population placing greater demands on an unsympathetic state authority?
2. Are Japanese families over time likely to employ a subtle policy of abandonment, towards the terminally ill aged, vesting responsibility in state authorities as was the unfortunate case in the institutionalization of mentally ill persons? If so, how should the issues be confronted in order to avoid unsettling outcomes?
3. How should the Japanese government go about developing policies and ethical guidelines that will maximize human dignity for terminally ill patients? Furthermore, how specific should such guidelines be?
4. How should national policies be implemented and with what attempts at a standard of national consistency?
5. What are the best vehicles for protecting the integrity of the family as a social unit of decision making while preserving and enhancing respect for persons through the medium of self assertion?
6. If there are changes in attitude occurring in the culture, how should health professionals be educated to pick up on signals when families conflict with individual preferences?

Sixthly, flowing from our understanding of policy an articulate overview of future projections is needed.

1. How does one accommodate to progressive forces emerging within the culture? Who has the right to enhance or subvert such trends?
2. Should pressure be placed on the Japanese government or any other organization to develop a new set of advocates or adjudicators to deal with the elderly?

Finally, it is important to create a research database to inform theoretical and policy analyses.

1. What kind of epidemiological and qualitative research should be encouraged to enhance our knowledge about the treatment of the terminally ill in Japan so as to arrive at greater respect and human dignity for this vulnerable population?

REFERENCES

Announcement from the Japan Geriatrics Society Ethics Committee (2004) The Terminal Care of the Elderly. *Japan Geriatrics and Gerontology International*, 4, 1–4.

Dworkin, G. (1988) *Theory and Practice of Autonomy*. Cambridge: Cambridge University Press.

Glick, S. (1997) Unlimited human anatomy – A cultural bias? *The New England Journal of Medicine*, March 27, 954–56.

Goodin, R. (1985) *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities*. Chicago: University of Chicago Press.

Hayashi, M. et al. (2000) Respecting autonomy in difficult medical settings: A questionable study in Japan. *Ethics and Behavior*, 10 (1), 51–63.

Higuchi, N. (1992) The patient's right to know of a cancer diagnosis: A comparison of Japanese paternalism and American self- determination. *Washburn Law Journal*, 31, 455–73.

Hoshino, K. (1995) Autonomous decision making and Japanese tradition. *Cambridge Quarterly of Healthcare Ethics,* 4, 71–4.

Ishiwata, R. and A. Sakai. (1994) The physician-patient relationship and medical ethics in Japan. *Cambridge Quarterly of Healthcare Ethics*, 3, 60–66.

Lambris, A. (2003) Informed consent of all? Not quite! A comparison of informed consent in the United States and Japan. *Temple International and Comparative Law Journal*, 17, 1, 237–59.

Loewy, E.H. (1991) *Freedom and community: The ethics of interdependence*. NewYork: SUNY Press.

Long, S.O. (2002) Life is more than a survey: Understanding attitudes towards euthanasia in Japan. *Theoretical Medicine*, 23, 305–19.

Macer, D. (1993) What can bioethics offer to Japanese culture? *Niechibunken Newsletter*, 15, 3, 3–6

Macklin, R. (1999) *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*. New York: Oxford University Press.

Mogi, N. and Y. Masuda. (2003) Effect of death education on self-determination in medical treatment in university students. *Geriatrics and Gerontology International*, 3, 200–207.

Morioka, M. (1989) *Brain-Dead Person*. Tokyo: Tokyo-Shoseki.

Pellegrino, E. (1992) Is truth telling to the patient a cultural artifact? *JAMA*, 268, 13, 1734–35.

Rendtorff, J.D. (2006) The Limitations and accomplishments of autonomy as a basic principle in bioethics and biolaw. In Weisstub, D.N and G.D. Pintos (eds.), *Human Rights and Health Care*. (Springer in press)

Smith, J.C. (1986) Ajase and Oedipus: Ideas of the self in Japanese and Western legal consciousness. *University of British Columbia Law Review*, 20, 341–77

Sulmasy, D. (2006) Dignity, rights, health care and human flourishing. In Weisstub, D.N. and G.D. Pintos (eds.), *Human Rights and Health Care*. (Springer in press)

Tanida, N. (1996) 'Bioethics' is subordinate to morality in Japan. *Bioethics*, 10, 3, 201–11.

Thomasma, D.C. (1997) Bioethics and international human rights. *Journal of Law, Medicine and Ethics*, 25, 295–306.

Weisstub, D.N. (1998) Roles in clinical and research ethics. In Weisstub, D.N. (ed.), *Research on Human Subjects: Ethics, Law and Social Policy*. Oxford: Elsevier Science.

_____. (1998) The ethical parameters of experimentation. In Weisstub, D.N. (ed.), *Research on Human Subjects: Ethics, Law and Social Policy*. Oxford: Elsevier Science.

_____. (2002) Honor, dignity and the framing of multiculturalist values. In Kretzmer, D. and E. Klein, *The Concept of Human Dignity in Human Rights Discourse*. The Hague: Kluwer Law International.

_____. (2003) An international perspective on Japanese mental health law: Ethics and policy. *Seishin Shinkeigaku Zasshi – Psychiatria et Neurologia Japonica*, 105(7), 881–83.

Weisstub, D.N. and J. Arboleda-Florez. (2000). Conflicts and crisis in Latin America. In Weisstub, D.N., A. Okasha and N. Saetorius (eds.), *Ethics, Culture and Psychiatry: International Perspectives*. London: American Psychiatric Press.

Weisstub, D.N. and T. Carney. (2006). Forensic mental health law reform in Japan: From criminal warehousing to broad-spectrum specialist services? *International Journal of Law and Psychiatry*. (in press)

Weisstub, D.N. and D.C. Thomasma. (2001). Human dignity, vulnerability, personhood. In Weisstub D.N., Thomasma, D.C. and C. Hervé (eds.), *Personhood and Health Care*. Dordrecht: Kluwer Academic Press.

Weisstub, D.N. and D.C. Thomasma. (2004). Moral capacity: The tension between professional nurture and universal nature. In Weisstub D.N. and D.C. Thomasma (eds.), *The Variables of Moral Capacity*. Dordrecht: Kluwer Academic Press.

Young, J. (2002) Morals, suicide and psychiatry: A view from Japan. *Bioethics*, 16, 5, 412–24

PART III

PLURALISM, RACE AND HEALTH

TERRY CARNEY

CHAPTER 12
CULTURE, COMMUNITY OR RIGHTS

Securing Health in a Post-Modern, Privatised World

INTRODUCTION

Autonomy or paternalism? State provision or respect for individual autonomy and markets? Adult guardianship and durable powers of attorney are emblematic of these contests (Carney and Singer 1986). Debates seem to have begun to turn decisively in favour of markets and individualism in many countries. Is it so? Are new philosophical balances and new forms of state organisation a product of postmodern contemporary society (Clarke 1998)? Or is policy more complicated, with the shape of government determined more by the elevation of neoliberalism as a political "rationality" than by philosophical precept (Beeson and Firth 1998)?

Certainly there is an argument that society is differently configured. Eckersley, for example, argues that five "-isms" are emblematic of modern western culture: 'economism' (greater reliance on markets), consumerism, postmodernism, pessimism (disconnection from society), and individualism (human autonomy) (1998, 11). Each has its assets and liabilities, of course. But his assessment is that the "cultural negatives are reinforcing each other, and we now lack the necessary cultural balances" (Eckersley 1998). Our sense of collective political and community agency may be neglected. This chapter explores the balance between individual and collective interests in selected laws enshrining health rights.

Is Health Amenable to Law? Health is one of those entitlements which international instruments on social, economic, and civil rights express in loose, rhetorical language, often hedged about with qualifiers such as being "subject to resources." Such welfare rights do not read like ready-made laws which await enactment. They sound more in the sphere of politics than of law (Carney 1991a). This is because *positive* rights, like health care, necessarily make claims on scarce resources; resources which are unequally distributed both within and between nations. Windy, unspecific language also tells us something else – that room for manoeuvre is needed when individual values or cultural expectations are plural or divergent, or when goals and standards of health care are hard to state. But is this simply a defining characteristic of such (positive) welfare rights, or is there a deeper issue? Is it just that the dialogue about welfare rights differs sharply from the familiar dialogue about civil rights?

On first impressions this seems to be the case. Traditional expressions of civil rights (like freedom from torture) actually "look" like real laws: their rights are concrete and precise, unlike their counterpart welfare rights. But then they generally

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 155–172.

guarantee a *negative right*; preserving a zone of freedom, or guaranteeing personal "autonomy." Rights "to be left alone." Is this the difference? Or are autonomy rights different from welfare rights because they do not lay claim on public resources? Or are they different because they reflect universally agreed values? Neither cuts much ice. Respect for privacy or autonomy is not a "free" good: its practical recognition depends upon funding for law enforcement and courts. Nor are the value choices of civil rights unproblematic. Individual choice or autonomy may not sit well with preferences some citizens have for group or family-based forms of decision making. Privileging autonomy – even under something as apparently mundane as durable power of attorney legislation – often disenfranchises citizens who prefer collective or informal means of organizing their affairs. Indeed, the very ease with which *civil* rights, like autonomy, can be written into legislation may be problematic, obscuring such subtleties.

What we can draw from counterpoising welfare and civil rights, is that *positive* entitlements are not easily written into law. If they are legislated, redress cannot readily be provided by the courts, or even by more innovative administrative tribunals. Both individual and collective rights (to distributional equity) often hinge on provision of more than protection of abstract entitlements to "choose." As Berlin (1969) puts it, there is an important difference between negative and positive liberty (Ferry 1994, 294); it is the difference between freedom *from* and freedom *to*. Law is much less able to secure the latter than the former. This is not to suggest that law does not indirectly assist in securing positive rights, such as through minimum standards or professional competence (professional registration and malpractice litigation), or in securing access to health care (public funding or subsidies for health costs), or in promoting health and safety (occupational health, environmental and health promotion). What it does tell us is that law is sparse at the very point where a vast thicket might be anticipated. It has little to say on the issues of public health, and nothing of value on resource allocation questions.

History demonstrates that this is not new. Not until 150 years ago did the British Parliament adopt Edwin Chadwick's *Public Health Act* 1848, specifically designed to improve public health (Hamlin 1995).[1] This legislation sought to control illness and disease mistakenly attributed to foul air and "vapours" (the "miasma" theory) (Tesh 1995). Clean water, adequate ventilation, living space, paving, drainage and sewerage were promoted (Reynolds 1997, 578). Not least because sanitation was more compatible with strong liberalism than was the economic intervention associated with imposed "quarantines" (Tesh 1995). Once modern "germ theory" gained sway, public health measures switched over to avoidance of contaminated conditions or contact with carriers of transmissible diseases.[2] This served the public well for perhaps a century.[3] *Structural* causes of ill-health fared poorly, however. Degraded or overcrowded living conditions, poor nutrition, and poverty attracted some attention while miasma was most prominent, but this rapidly waned due to an unwillingness to confront the social, economic, and political causes of disease (Tesh 1995, 1021–2). Little interest was shown in deciding between "social" and other origins of illness, or means for its prevention. Creation of the municipal government post of "medical officer of health" was a rare exception.[4] Instead; minimalist British models won support (Bidmeade and Reynolds 1997).

But is there a deeper question at stake here? Are welfare rights problematic because they interpose the "state into the sphere allocated to civil society or because they *interfere* with "autonomy rights"?

Autonomy and Civil Society? Respect for autonomy was certainly privileged by the British model in various ways, including as a basis for patient consent and as a check on coercive state powers over groups such as the mentally ill. Regulatory frameworks constructed to assure the quality and safety of food, water, and pharmaceutical products; or to provide licensing, peer accreditation, and review of practitioners – also respected autonomy indirectly in the sense that paternalistic state intervention was fairly circumscribed. Moreover law has been muted on issues such as access to health care (where its contribution may be more problematic anyway). But what is really demonstrated by its role in these core areas? Is conventional wisdom correct in thinking that individual autonomy was an embedded value within the old model? Does this value risk being loosened from its socket by technological challenges, multiculturalism, or postmodernism? The record puts this in doubt on several fronts. First on grounds of philosophical or political theory, and secondly on pragmatic grounds.

Rothstein explores the tension between individualism and collectivist action as the basis for setting the boundaries of state action, paying special attention to ideas of political liberalism (state neutrality and individual autonomy), and "communitarianism" (1998, 31). Ronald Dworkin's injunction that the state should treat citizens with "equal concern and respect" is one way of expressing the state neutrality principle. It is the basis for saying that autonomous choice trumps utilitarian calculus of the "greatest good," at least while it does not bring harm on self or others.

Communitarianism, though, involves privileging *collective* assessments, allowing individual choice to be negated by, say, a collective reading of the benefits of gender equality (or of reducing harms from public smoking). In other words, by preferring particular life choices over others. communitarian perspectives are comfortable with resting such initiatives on readings of common sentiments and cultural values, including endorsement of commitments to separateness and diversity (as in embracing multiculturalism with its "separate but equal" rubric (Rothstein 1998, 36, 39). They question the "atomist" notion of human nature, and draw attention to the communal settings within which people live their lives.

Dworkin accepted that some of these aspirations are worthy, but sought to justify state action to promote such goals not by acceptance of paternalism, but by the device of "volitional" paternalism. This sleight of hand legitimates, say, a ban on public smoking (by a minority of smokers) because all people embrace the higher or subsequent goal of a healthy life (Rothstein 1998, 37–8). The state, then, is merely protecting this long-range choice; a position sometimes called "soft" paternalism, or the "thank-you" theorem (retrospective consent derived from attainment of the goals). Walzer's answer, too, was to look for a third way, by arguing that different spheres of life call for different sets of distributional outcomes (1983). Voting rights are different from access to work or access to health care (Rothstein 1998, 40). Within these spheres individuals should be accorded equal measures of concern and respect, but each sphere would reflect historic or socially conditioned "settlements" of what constitutes fairness. Rothstein finds this acceptable as a statement of lived social reality, but problematic as the ground for a normative statement of the proper role of the state. This is because it leaves unchecked the power of a slim majority to impose their whims and prejudices on the rest of the population (1998, 40). It may be an acceptable foundation for social and cultural intercourse, but not for reconciling state action with *civil* society.

Expressed differently, as a political "rationality" for government action (as distinct from an abstract philosophical position), neoliberalism may not involve counterpoising autonomy and paternalism at all, however. Instead, individual freedom is conceived as an "*artifact of* particular strategies and modes of regulation rather than the *absence* of government intervention" (Beeson and Firth 1998, 218: emphasis added). So liberalism would govern through the "self-regulation of individuals who are, at once, the object and partner of those technologies of government through which political reason *becomes practical*" (emphasis added). This may square with postmodernism and is discussed in the next section. But first we might ask if this variation in the proportions of autonomy and state involvement is also to be read from the accumulated stock of laws and policies; enabling an empirical derivation of a set of core norms and boundaries, such as in critical areas like involuntary treatment of the mentally ill?

Consensus in Key Areas? Cause for serious doubt about certitudes in the mix of autonomy and paternalism arises in mental health.

It is true that the utilitarian-liberal precept of restricting detention for treatment to circumstances of threat to self or to others has permeated mental health law over the bulk of the past century or more (Curran 1978; Gostin 1983, Butler 1985). However, its influence has waxed and waned, and the restrictive legal approach has long had its critics who argue that it impedes provision of needed care (Jones 1980; Rose 1985; Wexler 1990). Consequently there have been phases where barriers to involuntary treatment have been eased, and the scope of what qualifies as illness as a basis for intervention has been broadened. A World Health Organisation (WHO) review in the 1950s, for instance, found judicial committal in disfavour as an entry gateway, with preference for medical committal at the behest of family or friends. This pattern still prevailed in the late 1970s (Curran 1978, 82, 88). While utilitarian liberalism was more influential in narrowing grounds for admission during the 1980s in Australia, contemporary reforms in the state of New South Wales to authorise early intervention management of schizophrenia marked yet another re-balancing (NSW Institute of Psychiatry 1998).[5]

Even when utilitarian liberalism does notionally inform the construction of mental health laws, the mix varies greatly. Australian law, for instance, provides that committal as an involuntary patient carries with it the authority to treat without consent (ECT and some other procedures are excepted), while Canadian law generally distinguishes between involuntary detention and involuntary treatment to a much greater degree, providing two cumulative avenues of review procedures before treatment authorities are free to impose treatment on a protesting patient. So the bastion of what constitutes civil society for the mentally ill proves to be very contingent and heavily contested. The boundary between civil society and the state is more fluid than was anticipated, altering both over time (historically) and between jurisdictions (comparatively).

Of course, this might be nothing more than an expression of a finely pitched philosophical contest (between autonomy and paternalism), one where the stakes are very high (i.e. where survival and future health/welfare may be on the line). Surely there is greater consensus about the form of basic laws which merely serve as "handmaidens," promoting the instrumental expression of individual desires? Sometimes this is precisely what law does: providing citizens with a *vehicle* for the expression of their autonomy. This is arguably what durable powers of attorney do. But provision of a vehicle does not necessarily mean that large numbers of people will be attracted to use it. There is the question of the "accessibility" of the law. Lack of use may mean that autonomy is compromised (rapacious relatives may subjugate and exploit a vulnerable person). Or, perversely, autonomy may actually *flourish* outside the law (because an extra-legal solution proves to be a *superior* avenue to the law).

Even if the legal device is used, it may or may not achieve its purpose: powers of attorney designed to perpetuate a person's wishes after they lose their capacity, may come to be used as an instrument serving third party interests, or some fraudulent purpose, for example. This is the question of fidelity to purpose (or the "reliability" of the legal instrument). And if there is a level of abuse (as inevitably will be the case) questions will arise about whether external monitoring or intervention is justified to reduce (or correct) that risk. This is the question of cost-benefit ratings of legal and extra-legal approaches. The same question occurs in the rating of different *kinds* of law (such as deciding between differing degrees of intervention, or of say formality in execution of instruments).

Should durable powers of attorney be presumed sound or suspect? Should they be placed on a public register? Should they be closely witnessed (as with a testamentary document) or be treated like ordinary consumer documents? Even here the law comes in many shapes and sizes (Carney 1999; 2001).

What "Is" Law? On the other hand, law is more than its text.

Identically phrased text may impact differently on the lives of affected citizens, as some adult guardianship studies show. Identically drafted statutes can produce quite different outcomes. The choice of adjudicative body matters, for instance. In the hands of the courts, consent to sterilisation laws tended to endorse *a prior* consensus struck between members of the family and the medical profession, whereas tribunals looked more closely at evidence, searched out underlying structural components, and gave more weight to the interests of the disabled person and welfare perspectives (Carney and Tait 1998). Autonomy rights "on the books" may be very different to those found "in practice" (as the legal realist movement established earlier this century).

Surrounding institutions make a difference too. Having an ombudsman-like "public advocate" agency enabled the tribunal in one jurisdiction to conform closely to its intended classical liberal stance of making orders only as a last resort, in accord with a "legal model" of intervention. However, its absence in an equivalent jurisdiction accounted for adoption of a more interventionist or "welfare" approach (Carney and Tait 1998).

What this suggests is that the *practical* realisation of autonomy rights is not automatic. It is not enough to select the autonomy value and draft up a law which nominally gives expression to that position. Nikolas Rose took a similar line about rights and legalism as a basis for mental health reform. “Rights discourse” was attractive on strategic grounds because of its political (rhetorical) power (1985, 214). But this power came from its conflation of three levels of discourse: moral discourse (the “worth of humans”) was said to be conflated both with a political discourse about the duties (and limits) of state action, and with a technical discourse about the best methods of regulation. Design and implementation of concrete programs of reform called for something more sophisticated.[6] Autonomy rights are open to the same analysis.

Rose demonstrated one of the ways in which this might be so in his review of the role of mental health tribunals as gate-keepers to admission. Ostensibly these tribunals protect the integrity and autonomy of the patient against precipitated admission decisions. Certainly their decisions differ from the professional assessments made by psychiatrists, whose conceptions of “evidence, modes of argument, techniques of judgement, and notions of proof” are at odds with those applied by the law (Rose 1985, 208). But the lay tribunals may apply a different logic again, mistaking the law, being “guided by ‘common sense’ understandings of madness” and being “influenced more by therapeutic goals”. As a result, selection of tribunals as the gatekeeper may simply “shift discretion to a different place, involve different agencies and establish new powers” (Rose 1985, 207). He conceded that there may well be advantages in involving these new sources of expertise. However, there is much more to it than a simplistic counterpoising of “professional discretion” against the “rights of the detained patient” (Rose 1985, 207).

One of the dimensions which is often overlooked is whether autonomy rights are “used” by those for whom they are provided. Enduring powers over health care are a good example, because they can empower a person to control critical health care – such as whether heroic treatment is administered. Laws authorising such instruments are often poorly publicized.[7] But formal usage by populations favourably disposed to their presence can remain low even *after* extensive education of how they work (in one study, personal education campaigns only boosted enduring health care utilisation rates from under half a percent to 18% among aged people discharged from the hospital) (Rubin et al. 1994). Dr Singer and others have tracked what people do with such information (1995). They conclude that having a process of “family discussion” is sufficient for many people, becoming an end in itself (relieving friends and relatives of the “burden of uncertainty” of deciding without knowing how the person *actually* felt).

What this demonstrates is that the social *process* precipitated by newly acquired knowledge of how enduring powers of attorney operate, proved to be more important than the formal legalities of actually drawing one up. Differences in philosophical values matter too. Kelner found that some people like to stay in “control” (projecting personal autonomy of decision onto any future capacity), while others take a passive or fatalistic position – “delegating” those decisions to other people (or systems); a choice associated with education and social class (1995). Singer observes that, traditionally, advance care planning “is viewed as a silent, asocial, acontextual event that occurs within the doctor-patient relationship and culminates in completion of a written advance directive form." Whereas, in reality, it is a:

> [V]erbal, social, contextual process that occurs between people and their loved ones and culminates in a proxy which is prepared for future substitute decision making (1995).

But where does the "autonomy" entry in the social policy ledger stand for such people? Is it an "abuse" that the current law is fashioned in a way which is unappealing to people who hold these values? Are they *less* prone to abuse because no legally binding instructions or authorities have been executed? Or is their plight more hidden from public view, and their status rendered more uncertain, because their *carers* do not know where they stand legally? We have little way of knowing. Though many of us may feel more comfortable with injecting some semblance of legal norms or legal structure into the arena, this may be a mistake.

That said, what is it that these various new "-isms" purport to add to the terms of the established debates?

POSTMODERNISM, CONTRACTUALISM, OR COMMUNITARIANISM/CITIZENSHIP

Several new theoretical paradigms lay claim to explain changes said to be emblematic of contemporary social and economic conditions, or "postmodernism." In this section we will review what they might have to offer to our understanding of respect by the law for personal autonomy.

Postmodernism? Eckersley sums up postmodernism as describing:

> A world coming to terms with its limitations, including the "modern" dream of creating a perfect social order through the rational instruments of science, technology, and bureaucracy. It is a world characterized by relativism, pluralism, ambivalence, ambiguity, transience, fragmentation, and contingency (1998, 11).

The state is subject to pressure, both to shrink its role and to be more accommodating of diversity (Hoggett and Thompson 1998, 237). This is especially true in societies where high levels of immigration have created heterogeneous, "multi-cultural" populations, or where globalisation, new communication technologies, and media have begun to dissolve the boundaries of national identity and national management (Davidson 1997). It takes the form of loss of faith in "command and control" forms of state intervention, with the state either withdrawing (full privatisation) or reinventing itself (Latham 1998; Rothstein 1998).

One possible reinvention of the state sees it confine itself to setting down the terms and conditions for social intercourse, or the policy goals to be pursued; otherwise known as "framework" laws (Carney 1991b, 18–20; Thompson 1998, 246–7 and Rothstein 1998, 200; Hoggett). Inevitably, this expands the space for civil society by expanding the scope of choice and discretion (Simon 1983). Such laws articulate collective expectations and values in the form of coarse-grained "standards" (not rules). The concrete content commonly captured in the rules of traditional "prescriptive" law is instead supplied some other way. Simon, for example, envisaged that standards might be supplied by collegiate and "professional" processes including "decentralized enforcement proceedings in which citizens participate" (1983, 1242). Ethical standards and professional culture would substitute for legislative norms.[8] Of course this opportunity arises whenever the law withdraws from an area; Simon's professionalism model, or contemporary preferences for creation of "markets" by creating a sharp divide between (government) purchaser and (private contractor) providers – are simply two ways of achieving that.[9]

Another way in which this might be realised is by fostering what Handler calls a "dialogic community," such as by creating more localised, open-textured, and "responsive" administrative locations (1988). Cochrane sees localisation (or associations) supplying necessary elements of active, autonomous citizenship (1998, 255–60). This may enable the state to avoid over-reaching itself or setting inappropriate substantive objectives, and instead look at creating suitable processes (or dialogic spaces).[10] As Teubner has argued, this involves recognising the advantage of creating self-governing spheres; self-contained "domains" with their own internal logic (Handler 1988, 1047). This expression of interdependence may arise naturally outside the law (and traditional boundaries of the state), or it may arise in areas where discretion is provided "[I]t asks: in these spaces, what are the conditions necessary for community" (Handler 1988, 1001)?

In either setting it is plain that these conditions must include adequate guarantees against oppression from inequalities of power and subjection to hierarchy. However, in situations of caring for the frail or vulnerable the participatory "dialogic community" only very rarely emerges, instead succumbing to forms of "legal-bureaucratic" relationships. This might reflect the sway held by the dominant conception of a "negative/protective" conception of rights as enshrined in "liberal legalism" (Handler 1988, 1018). Too little attention is given to actively *fostering* civic participation (as sought by republican citizenship or even classical liberalism) (Rosales 1998). Another difficulty is the opportunity presented for inappropriate values to find expression in these settings, or for abuses to flourish unchecked. While postmodernism would retort that law is heavily value laden (and historically contingent) in any event, this is an important question. But is the risk greater when the space is created in the interstices of law than when social practice allows it to emerge in extra-legal "dialogic spaces" in the community domain? This is not just a theoretical question, as the discussion of durable powers legislation showed earlier.

Where the line is best drawn between the sectors of public provision (e.g. decisions made by adult guardianship courts), private-ordering conducted within a legislatively structured framework (as with durable powers legislation) or community ordering (reliance on civil society) is largely a public policy judgement, which varies greatly from country to country. North American commentators see public guardianship as posing the greater risk) and advocate durable powers as the preferred solution (often seeking to *immunize* them against being overturned by guardianship courts) (Jost, 1980; Sherman 1980; Alexander 1990). While extremely strange to Australasian eyes, this preference is explained by the cursory time and attention given to guardianship by U.S. Probate courts, and by the number of avaricious "ambulance chasers" who allegedly make themselves available for court appointment.[11] That said, there is much common ground across the common law world (Carney 2001). The U.S. *Uniform Probate Code*, issued by the National Conference of Commissioners on Uniform Laws, for example, now reflects most of the basic architecture incorporated into substantive guardianship law under Australasian reforms in the 1980s.[12] However, as in New Zealand (and the Northern Terrritory), it retains courts as the adjudicative body. This may be its undoing (Carney and Tait 1997).

Autonomy in the "Contractualist" State One well -charted trend line associated with postmodernism is the decrease of the role of the state (Argy 1998, Caragata 1998, 279; Rothstein 1998). Just as debate about social citizenship rights became a shorthand way of describing the rise of the post-war *bureaucratic* welfare state, so reflections on "contractualism" may be seen as emblematic of its decline, and its transformation. Contractualism is a word which resonates with a return to individualism, both in greater reliance on individual provision than on state services or regulation, and in the return of contractual relations. The rise of "contractualism," with its individualisation of social relationships, is a feature of contemporary social policy,[13] though one which Hay attributes to the power of ideas rather than any ineluctable "logic" of the market or social polity (1998, 529). Contractualism, as the term implies, injects ideas of private contract into the way the state relates to citizens (such as contracting-out delivery of mental health or other services) [14] or as a precondition to gaining access to public benefits and services (e.g. shifting income security from a "status" to a "contract") (Weatherley 1994; Carney 1998b).

As Argy observes (1998, 49–53), it reflects a deliberate policy of withdrawing the state from its (Keynesian) regulatory oversight of such things as credit, trade, and wage relations (Kosonen 1995, 820), better accommodating the features of postmodern culture and globalisation (Walby 1995). It allows the state to take many new forms (it does not just make laws and deliver services) and enter many more settings than it once did (private entrepreneurs may take over state responsibilities for aged care, or the family may become an agent of state regulation). Commentators speak of this as the state becoming more "differentiated." In its contemporary form the state is now characterised by greater fragmentation, flexibility, and sensitivity to markets (Clarke and Newman 1993, 47). Hallmarks include desegregation, localisation, and variation in patterns of service provision (Latham 1998, 6). Individual contractual agreements are becoming a prime way of achieving this. This has both assets and drawbacks.

Because contractualism is a prime expression of liberalism, its drawbacks are accentuated under neoliberal economic policies (or classical 19th century liberalism), where the logic of the economic domain supplants socio-political considerations (Rosales 1998, 261). Here individual choice is a zone of "negative" liberty which is immune from state interference; moral responsibility is attributed to all actions; and state engineered distributional equality is not a valid goal. Liberalism, on the other hand, celebrates a relationship between the individual and the state in creating the *conditions* for civic society to flourish. As Rosales argues, "An egalitarian and universalist model of socio-economic welfare is a *constitutive* feature of liberalism... a liberal policy is an active policy in matters of rights" (1998, 268: emphasis added).

Contractualism, though, dilutes the impact of rules or standards set by Parliament, expanding the space for the exercise of either private discretion and "brokerage" (as in much private health ordering) or the administrative discretion of agents of the state (public servants, or private contractors engaged by the state). This can magnify inequalities of power. Contracts may be written in loose, subjective language, and often they are not transparent to public scrutiny. Negotiation and compliance may be left to the parties (or private mediating agencies). Weberian ideas of state objectivity, neutrality, and arms-length administration are unlikely to apply, and access to courts or tribunals is withdrawn or circumscribed.[15] True liberalism seeks to offset those risks by investing in state provided protections as the "opportunity costs of citizenship" (Rosales 1998, 264).

Of course contractualism has its benefits too. Western family law has been criticised for legislating to entrench values of sexism, (male) hierarchies of power or notions of female dependency; values which may erode more rapidly under a system of private ordering (Singer 1992, 1532–3). Contractualism is also touted as promoting social participation by widening access to social goods, or even to work (Pixley 1993, 11, 31), or by fostering social capital in the form of "mutuality" (reciprocal relations of citizens to the state) (Wilson 1994, 53), or by enhancing flexibility and accountability (Nelken 1987, 209–12). One of these claims is the emphasis on tailoring the formation of "self-regulated" social relationships (Yeatman 1995, 132).

Contractualism is problematic for adults, but at least there is general acceptance of their capacity for autonomous action, and of the legal right to express that autonomy (unless contrary to the public interest or private welfare). As Yeatman observes, this leaves room for a feminist perspective to modulate its application to them. Adults can agree among themselves to adopt a "combined ethic of care and empowerment" in place of contractualism's rampant individualism. This is plausible for adults with capacity, but what if capacity has been lost? Here the mediating role could be entrusted to substitute decision makers acting as "trustees." The risk, though, is that the ethic of "care" may degenerate into a sexist, individualist standard of "good" mothering (Yeatman 1995, 135), serving to perpetuate disempowerment While the traditional protective role of public agencies of the state, such as adult guardianship courts, is equally open to criticism that its vaunted "best interests" test is an artifice (Harmon 1990), at least this operates as a *public* space. Because it is a public space it has the attraction of being more contestable than is the privatised space implicit in contractualist policies for the vulnerable.

Communitarianism or Citizenship? Again, durable powers of attorney provide us with our point of departure about communitarian or citizenship paradigms. Is it a mistake to concentrate on ways of preserving the capacity for *individual* will to find expression after incapacity? Is the primary need for people vulnerable to loss of decision making that of empowering *families* (or carers), as the English Law Commission thought with its 1995 proposal to enact a new "general authority to act reasonably?"[16] Or of creating spaces for family dialogue, as in Fentimans's "conversation" model of decision making (1989, 841)? Are we barking up the wrong tree by focusing on leaving behind "directions" (on the analogy with wills), or on a need to confer "authority to act" (carrying forward the 13th century ideas of "committees" of the estate or person) (Neugebauer 1978)? Is "advocacy" a better avenue? What is the line of ethical or practical accountability?

Communitarian scholars in North America tend to argue that a sound ethical base *will* emerge if there is space for "extended, un-coerced, open conversation," allowing the Aristotelian idea of consensus of "*phronesis*, or practical knowledge" to flourish (Handler 1988, 1063–4). For instance, there may be some merit in the United Kingdom Law Commission idea to the extent that it starts by "mapping" law to an existing social reality. But it surely goes too far to suggest that all such informal arrangements will be ethically grounded, or fair. A better way of catering to that need for a sense of "connectedness" with the contextualised lives of people needing substitute decision makers is through so-called "Ulysses" contracts. These have the advantage of giving legal force to basic "guideline" statements of the *affected* person, stipulating how an identified *group* of people – such as family or friends – are expected to manage, in their discretion, a future state such as mental illness (Nicholson 1995). They are much more flexible than the individualised powers available under durable welfare powers, or in South Australia and Victoria – over medical issues (Atkin 1988a, 348; 1988b, 369), and even over the "extended narrative" (long formats) which can be provided as an option in writing a durable power of attorney (an alternative proposed by the Queensland Law Reform Commission).[17]

But what is gained by such reforms? Is it right to allow people to assign to a group of people the swathe of coercive, intrusive, and flexible powers which "Ulysses" agreements entail? Can people adequately anticipate the fine detail of what they would wish to do, or what their values and feelings are likely to be in a given set of future circumstances? Is that reading more legitimate than its alternatives? Should we privilege the extended "novelette," with its very elaborate written instructions, over other social processes? Ferry's francophone influenced paradigm (of "methodological communitarianism") balks at accepting the cultural relativism implicit in the notion of *phronesis*, preferring a methodology which transcends context and permits *universal* ethical principles to be derived and applied (1994, 299–300). But this calls for breaking down structural "limitations" on communication, or for the cultivation of the political institutions and cultural conventions of a genuinely pluralist and "open society" (Ferry 1994, 302–3).

Handler's guarded endorsement of dialogic community ideas is reassuring on these points, spelling out in great detail both the magnitude and complexity of the task of creating genuine dialogic spaces either within the bureaucracy (his main focus) or externally (as many continental theorists prefer). Notions of "understanding *and* co-operation" are seen as central moral values (Handler 1988, 1076: writer's emphasis). Relationships of *trust* are to be cultivated in place of mere mechanical contractual dealings, [18] and community movements are to be mobilised (particularly for dependent clients (1988, 1078, 1108, 1112). His analysis is very mindful of the powerful countervailing forces at work, including under-resourcing, power imbalances or unprofessional behaviour. Certainly, the dialogic community, and the communitarian ethic it reflects (Mac Intyre 1981), is a fragile alternative to legal liberalism and the associated legal-bureaucratic pattern characteristic of the post-war welfare state. Yet, as the Weberian model of law and administration crumbles and shrinks, it reinstates the reliance on the voluntarism, community support, and private provision emblematic of 19th century welfare and community organisations (Finlayson 1994). Alternatives like the dialogic community call for ever closer scrutiny – however fragile or contingent they may prove to be.

As Fraser and Gordon argue, citizenship theory does not resonate in North America, accustomed as it is to simple dichotomy between charity and "contract" (1994). In substance, however, this reading of communitarianism equates with what is elsewhere termed "neo-republican" citizenship (Van Gunsteren 1994, 45). Citizenship concepts theorised by European writers provide a conceptual map of the welfare state which also enables a distinction to be drawn between "active" and passive forms of state action, and between individual and collective expressions of welfare.[19] "Social" citizenship as enunciated by T.H. Marshall in the 1940s was one of three interlocking sets of rights, built out from the "civil" (legal process) and "political process" rights (such as the franchise) consolidated in 18th and 19th century Britain. "Social" rights were the principal new "good" associated with the 20th century welfare state (Marshall 1973). Social rights to social "participation" joined guarantees of political and civil rights (Harris 1987). Equality of access to such *substantive* rights is *constitutive* of citizenship status (not derivative from it) (Crowley 1998, 170).

Offered unconditionally, this is a passive status like that of the liberal institution of property (as U.S. conceptions of welfare as the "new property" had recognised) (Reich 1964).[20] Negative autonomy of this character may be a basis for guaranteeing necessities of life. But it does nothing to counter social isolation, or the outsider status which may stem from joining the category of recipients of welfare (or the "stigma badge" evident from its parsimonious level of support) (Moon 1993). On the other hand, social rights of citizenship can also be thought of as the *ingredient* necessary to found the "activity" of social participation by citizens, mimicking the characteristic feature of liberalism (Oldfield 1990; Leisink and Coenen 1993). This (civic republican) portrayal of a more "dynamic" (reciprocal) relationship between civil society and the state, focuses more on what people *do* as distinct from what they *get* (Davidson 1997). It also has the attraction of recognising a moral responsibility of the state in protecting its vulnerable citizens irrespective of fault. And, because its focus is on the *goal* of "participation" rather than (statist) *means* for achieving distributional equity, it is comfortable with contractual or other private-ordering approaches for the achievement of that goal, subject only to asking if it "works." A pragmatic strand it has in common with liberalism as a "political rationality" (Beeson and Firth 1998, 218).

That is not to say that the active version of citizenship is entirely unproblematic. It may be too vague an idea to take us very far (Goodin and LeGrande 1987, 12); or, as with virulent contractualism, Dahrendorf may be right to fear that it is code for opening the door to "the visible hand of rulers who tell people what to do" (1994, 13). This is compounded if welfare safety nets are withdrawn, particularly under "citizenship of contribution" formulations popularised by conservative administrations in Britain (or "workfare" in Australia and the United States)

(Finlayson 1994, 9, 13–16). Active citizenship, then, is an imperfect benchmark. But, as mentioned, its saving grace is its acceptance of the language of a duty to assist people to participate in the life of the community; a duty which *can* ground positive rights to the *means* which citizens may require to realise their theoretical rights to autonomy of choice. An entitlement which *can* be conferred by laws written in new, more "relational" forms, and be adequately protected by more flexible, informal, and mediation forms of review (Carney 1991b; 1993).[21]

Tribunals (with lawyers in the minority), for instance, have been found to out-perform courts when dealing with substitute decision making (Carney and Tait 1997). The positive entitlements envisioned by active citizenship participation, then, need not remain mere weasel words whose realisation lies outside the province of law. Rather it is the contraction of the state which may be the more significant inhibiting factor to achieving distributional justice.

CONCLUSION

What we have seen is that there are at least two ways in which autonomy interests may be expressed; first, in terms of protection against their *negation*; and, second, in terms of positively *securing* their enjoyment. Social citizenship rights are founded in social *relations*; it is not simply a question of the state providing a new entitlement (what the person *gets*) by making utilitarian policy calculations about what is or is not in the interests of the greatest good for the greatest number. It involves constructing *active* opportunities for the citizen to realise citizenship through what the person *does* (Davidson 1997).

That is what substitute decision making laws – in their various forms – seek to do. Sometimes this is done by leaving civil society to work out what is best, free of special legal interventions to facilitate that planning. Other times this occurs by providing a special "conduit" for the expression of those plans – as with durable power of attorney laws. And sometimes by providing court avenues for reviewing those instruments, or for making new orders which over-ride or fill the gaps in those plans (adult guardianship). At a more abstract level, what is being decided here is whether law has a role to play in fostering environments where "positive" or "developmental" or more simply "*social*" rights may flourish. Ultimately, such rights rest in the application of the "equality principle," which is why their realisation has been so dependent upon the distributive arm of the welfare state over much of the course of the 20th century. If they are not to be trumped by competing policy considerations, they must be expressed as "ranking interests" in their own right; they cannot simply be derived from the playing out of market power (whether economic, or reflective of differential access to knowledge, or psychological stamina) in shaping outcomes. Social reciprocity is the nub of this thesis; that citizen and state owe mutually responsible duties to each other, and autonomy is not simply a "good" owed unconditionally to the citizen in standard dollops.

It is that reciprocity between citizens which builds the case for equivalent rights for adults in the aftermath of the transformation of the welfare state into the "bargaining" or contractualist state spawned by contemporary values and trends, which seems likely to dominate at least the early stages of the 21st century. It is argued here that health consumers are vulnerable to erosion of their (few) public sector rights, on two main fronts. They are vulnerable in a world of shrinking resources, which prioritises the rare and the costly individual claims that tug at the public heartstrings (like premature babies). And they are also vulnerable to the rise of centrifugal moral forces associated with the rise of pluralism (often emblematic of that diverse body of scholarship travelling under the banner of "postmodernism"). Plainly, privatisation risks accentuating those dangers.

This threatens distributional justice. Diagnosis is comparatively easy. What is problematic is finding a convincing foundation for a new approach. The reciprocity characteristics of communitarian or genuinely contractual models make some sense. However, less radical measures, such as tribunals or other "popular" justice institutions may also form part of this more promising synthesis.[22]

NOTES

[1] The Act crowned a campaign led by social reformers, such as Edwin Chadwick, and others, over the previous decade or more (Hamlin 1995). Its rationale is now disputed; its real basis shrouded by the mists of the very imperfect state of medical knowledge at the time (Tesh 1995).

[2] Notification, quarantine, and related powers to control infectious disease were added after 1848.

[3] Clean water, adequate sewerage, and food standards account for most (perhaps 80%) of the improvements in death rates and life expectancy in Australia in the first half of the 20th century. Hetzel attributed most of the later gains to pharmacological advances and improvements in the quality of the environment for infants (assisted by post-natal "Baby Health Center" initiatives), pointing out that the life expectancy gains accrued mainly to the "young" population cohort, rather than being dispersed across all age groups (Hetzel 1980, 27).

[4] This was introduced by amendments in 1875 in Britain. Rumsey (a physician and lobbyist) argued for the appointment of local doctors to the post of "medical officer of health" so that their "street credibility" could be harnessed (with community support) to intercede with employers or landlords to effect practical improvement in occupational and housing conditions (Hamlin 1995, 1028).

[5] The legislation creates a new category of "mentally disordered person" (encompassing a person acting irrationally in a lay sense) and allows periods of detention and treatment of up to three days (but not more than three such periods per month): *Mental Health Act 1990*. (NSW Institute of Psychiatry 1998, 25).

[6] Rose charged that rights language is unsatisfactory in several ways: "In the calculation of priorities or the resolution of conflicts, for conceptualizing or defending freedoms, for characterizing or evaluation decision making processes, for regulating or improving them, or for analyzing for transforming the powers of expertise over those subject to it." He went on to say that it "sidesteps the ethical issues, by smuggling in an unanalysed morality concerning the value and attributes of humans and the rules of just conduct." Finally, "It evades the political issues by its inability to confront the question of the distribution of scarce resources amongst priorities and by disguising the politics of its own utilization of legal mechanisms for the exercise of political power" (Rose 1985, 214–5).

[7] Surprisingly, few South Australians seeking control over management of care for their terminal illness were aware that laws to this effect had already been in operation for nearly a decade (Ashby and Wakefield 1993).

[8] Simon argued that in choosing "professionalizing" route ahead of its more democratic (or "market" oriented) "proletarianizing" alternative, his solution at least had the attraction of "[P]romis[ing] to overcome some of the deficiencies of Weberian bureaucracy as an instrument of control and, by extending the reformer's own mode of life and work, to create valuable allies for her." However, "[T]he disadvantages are, first, that if the strategy fails to inculcate the reformer's perspective, organisational autonomy may be used in ways that will frustrate her ends; and second, that the expansion of professional status dilutes the exclusivity of the positions and perhaps the privileges of the reformer and her present allies" (1983, 1262).

[9] It happens when child protection laws retreat from a welfare or "child-saving" preventive mandate to focus instead on tangible and immediate harms – the vacated ground is then free to be occupied by the family, voluntary self-help groups, professional social workers employed by non-government agencies (Carney 1998a).

[10] A body of mainly US scholarship argues a more modest case, suggesting that substantive objectives of the law are appropriate, but should be re-cast to promote "therapeutic" goals where this is not inconsistent with other values (Wexler 1990; Levine 1993; Perlin 1993).

[11] George Alexander, personal communication, July 1998.

[12] National Conference of Commissioners on Uniform State Laws, *Draft Amendments to Uniform Probate Code Article 5 – Guardianship*, Meeting 107th Year, Cleveland, Ohio, July 24–31, 1998.

[13] Yeatman provides a good review of the elements and implications of contractualism (1995).

[14] See, for instance, the discussion by Hollingsworth (1996) and Prager (1992).

[15] This is elaborated elsewhere (Carney 1996).

[16] In the event that no enduring power or adult guardianship order was existent, this provision would validate acts undertaken, in good faith, for the personal welfare or health care of a person who does or is reasonably believed to lack capacity, and would extend to pledging credit, organising roof repairs, and such like. As Bartlett puts it, this "is a startling and novel approach" (1998; 1997).

[17] Queensland Law Reform Commission, *Assisted and Substituted Decisions: Decision making By and For People with a Decision-Making Disability*. Brisbane, QLRC, June 1996 [Report No. 49, 3 Vols], 201-4. [Subsequently "QLRC"] at 102–4.

[18] Simon's decentralised professionalism may be a partial guarantor here (1983).

[19] These debates within citizenship theory are well summarised by writers such as Stewart (1995), Rees (1995), and Moon (1993).

[20] Simon (1986) pointed out that resort to concepts of property rather impedes redistributive goals.

[21] See further, Carney (1994; 1996). Conciliation or mediation of complex relational disputes appears to be superior to classical "adjudication" of them (Carney 1998a).

[22] Such as continental multi-disciplinary children's courts or Australia's experiment with tribunals to decide adult guardianship questions (Carney and Tait 1997).

REFERENCES

Alexander, G. (1990) Avoiding guardianship. *Journal of Elder Abuse and Neglect* 2, 163–75.

Argy, F. (1998) *Australia at the Crossroads: Radical Free Market or a Progressive Liberalism?* Allen and Unwin, Sydney.

Ashby, M. and Wakefield, M (1993) Attitudes to some aspects of death and dying, living wills and substituted health care decision making in South Australia: Public opinion survey for a parliamentary select committee. *Palliative Medicine 1993*, 273–82.

Atkin, W. (1988a) The courts, family control, and disability – aspects of New Zealand's protection of Personal and Property Rights Act 1988. *Victoria University of Wellington Law Review* 18, 345–65.

_____. (1988b) Enduring powers of attorney in New Zealand. *New Zealand Law Journal* 368–9.

Bartlett, P. (1997) The consequences of incapacity. *Web Journal of Current Legal Issues*. University of Newcastle on Tyne website (http://webjcli.ncl.ac.uk/1997/issue4/bartle4.html) at 6–7.

_____. (1998) The general authority to act reasonably: The benefits and pitfalls of broad legislation empowering carers. Paper presented at the 23rd Congress of the International Academy of Law and Mental Health, Paris, Friday, July 3, 1998: p. 4.

Beeson, M. and Firth, A. (1998) Neoliberalism as a political rationality: Australian public policy since the 1980s. *Journal of Sociology* 34, 215–31.

Berlin, I. (1969) *Four Essays on Liberty*. Oxford University Press, London.

Bidmeade, I. and Reynolds, C. (1997) *Public Health Law in Australia: Its Current State and Future Directions*. AGPS, Canberra.

Butler, T. (1985) *Mental Health, Social Policy and the Law.* Macmillan, London.

Caragata, P. (1998) From welfare state to optimal size of government. *Agenda* 5, 277–87.

Carney, T. (1991a) Social security: Dialogue or closure? In P. Alston and G. Brennan (Eds.), *The UN Children's Convention and Australia*. HREOC, ANU Center for International and Public Law, ACOSS, Canberra: pp. 53–61.

_____. (1991b) *Law at the Margins: Towards Social Participation*. Oxford University Press, Melbourne.

_____. (1993) Special needs children and human rights: Relational change under the rights banner? *Australian Disability Review* 3, 6–21.

_____. (1994) Client rights and system integrity in the relational state. In J. Disney and L. Briggs (Eds.), *Social Security Policy: Issues and Options*. AGPS, Canberra: pp. 191–208.

_____. (1996) Welfare appeals and the ARC Report: "To ssat or not to ssat; is that the question?" *Australian Journal of Administrative Law*, 4, 25–36.

_____. (1998a) Merits review of "contractual" social security payments. *Journal of Social Security Law,* 5, 18–43.

_____. (1998b) Liberalism or distributional justice: The morality of child welfare laws. In M. King (Ed.), *Moral Agendas for Children's Welfare*. Routledge, London: pp. 53–73.

_____. (1999) Abuse of Enduring Powers of Attorney – Lessons From the Australian Tribunal Experiment? 18 *New Zealand Universities Law Review*, 18, 481–508.

_____. (2001) Globalisation and guardianship: Harmonisation or (Postmodern) diversity? *International Journal of Law and Psychiatry*, 24, 95–116.

Carney, T. and Singer, P. (1986) *Ethical and Legal Issues in Guardianship Options for Intellectually Disadvantaged People*. AGPS, Canberra.

Carney, T. and Tait, D. (1997) *The Adult Guardianship Experiment: Tribunals and Popular Justice*. Federation Press, Sydney.

_____. (1998) Adult guardianship: Narrative readings in the "Shadow" of the law? *International Journal of Law and Psychiatry,* 21, 147–62.

Clarke, J. 1998. Thriving on Chaos? Managerialism and social welfare. In Carter, J., (Ed.), *Postmodernity and the Fragmentation of Welfare*. Routledge, London: pp. 171–86.

Clarke, J. and Newman, J. (1993) Managing to survive: Dilemmas of changing organizational forms in the public sector. In N. Deakin and R. Page (Eds.), *The Cost of Welfare*. Avebury, Aldershot: pp. 46–63.

Cochrane, A. (1998) Globalization, fragmentation, and local welfare citizenship. In J. Carter (Ed.), *Postmodernity and the Fragmentation of Welfare*. Routledge, London: pp. 25–66

Crowley, J. (1998) The national dimension of citizenship in T.H. Marshall. *Citizenship Studies* 2, 165–78.

Curran, W. (1978) Comparative analysis of mental health legislation in forty-three countries: A discussion of historical trends. *International Journal of Law and Psychiatry* 1, 79–92.

Dahrendorf, R. (1994) The changing quality of citizenship. In B. Van Steenbergen (Ed.), *The Condition of Citizenship*. Sage, London: pp. 10–19.

Davidson, A. (1997) *From Subject to Citizen: Australian Citizenship in the Twentieth Century*. Cambridge University Press, Cambridge.

Eckersley, R. (1998) Redefining progress: Shaping the future to human needs. *Family Matters* 51, 6–12.

Fentiman, L. (1989) Privacy and personhood revisited: A new framework for substitute decision making for the incompetent, incurably ill adult. *George Washington Law Review* 57, 801–46.

Ferry, J.M. (1994) Approaches to liberty: Outline for a "methodological communitarianism." *Ratio Juris* 7, 291–307.

Finlayson, G. (1994) *Citizen, State, and Social Welfare in Britain, 1830–1990*. Clarendon Press, Oxford.

Fraser, N. and Gordon, L. (1994) Civil citizenship against social citizenship? On the ideology of contract-versus-charity. In B. Van Steenbergen (Ed.), *The Condition of Citizenship*. Sage, London: pp. 90–107.

Goodin, R. and LeGrande, J. (1987) *Not Only the Poor*. Allen and Unwin, London.

Gostin, L. (1983) Contemporary social historical perspectives on Mental Health Reform. *Journal of Law and Society* 10, 47–70.

Hamlin, C. (1995) Finding a function for public health: Disease theory or political philosophy? *Journal of Health Politics, Policy and Law* 20, 1001–24.

Handler, J. (1988) Dependent people, the state, and the modern/postmodern search for the dialogic community. *UCLS Law Review* 35, 999–1113.

Harmon, L. (1990) Falling off the vine: Legal fictions and the doctrine of substituted judgment. *Yale Law Journal* 100, 1–71.

Harris, D. (1987) *Justifying State Welfare: The New Right Versus the Old Left.* Basil Blackwell, Oxford.

Hay, C. (1998) Globalization, welfare retrenchment and the "logic of no alternative": Why second-best won't do. *Journal of Social Policy* 27, 525–32.

Hetzel, B. (1980) *Health and Australian Society*. Penguin, Melbourne.

Hoggett, P. and Thompson, S. (1998) The delivery of welfare: The associationist vision. In J. Carter (Ed.), *Postmodernity and the Fragmentation of Welfare*. Routledge, London: pp. 237–51.

Hollingsworth, E. (1996) Mental health services in England: The 1990s. *International Journal of Law and Psychiatry* 19, 309–25.

Jones, K. (1980) The limitations of the legal approach to mental health. *International Journal of Law and Psychiatry* 3, 1–15.

Jost, D. (1980) The Illinois guardianship for disabled adults legislation of 1978 and 1979: Protecting the disabled from their zealous protectors. *Kent Law Review* 56, 1087–105.

Kelner, M. (1995) Activists and delegators: Elderly patients' preferences about control at the end of life. *Social Science and Medicine* 41, 537–45.

Kosonen, P. (1995) European welfare state models: Converging trends. *International Journal of Sociology* 25, 81–127.

Kymlicka, W and Norman, W. (1994) Return of the citizen: A survey of recent work on citizenship theory. *Ethics* 104, 352–81.

Latham, M. (1998) *Civilizing Global Capital*. Allen and Unwin, Sydney.

Leisink, P. and Coenen, H. (1993) Work and citizenship in the New Europe. In H. Coenen and P. Leisink (Eds.), *Work and Citizenship in the New Europe.* Edward Elgar, Aldershot: pp. 1–32.

Levine, M.A. (1993) A therapeutic jurisprudence analysis of mandated reporting of child maltreatment by psychotherapist. *New York Law School Journal of Human Rights* 10, 711.

MacIntyre, A. (1981) *After Virtue: A Study in Moral Theory*. Duckworth, London.

Marshall, T. (1973) *Sociology at the Crossroads and Other Essays*. Heinemann, London.

Moon, J. (1993) Citizenship and welfare: Social democratic and liberal perspectives. In W. Wilson (Ed.), *Sociology and the Pubic Agenda*. Newbury Park, CA: pp. 97–118.

Nelken, D. (1987) The use of contracts as a social work technique. *Current Legal Problems* 40, 207–32.

Neugebauer, R. (1978) Treatment of the mentally ill in medieval and early modern England: A reappraisal. *Journal of the History of the Behavioural Sciences* 14, 158–69.

Nicholson, R. (1995) Waving the magic wand: Solving key legal issues relating to intellectual disability. *Journal of Law and Medicine* 2, 271–292.

NSW Institute of Psychiatry. (1998) *Mental Health Guide Book*. Institute of Psychiatry, Sydney.

Oldfield, A. (1990) Citizenship: An unnatural practice? *Political Quarterly* 61, 177–87.

Perlin, M. (1993) What is therapeutic jurisprudence? *New York Law School Journal of Human Rights* 10, 623.

Pixley, J. (1993) *Citizenship and Employment: Investigating Post-Industrial Options*. Cambridge University Press, Hong Kong.

Prager, J. (1992) Contracting-out: Theory and policy. *New York University Journal of International Law and Politics* 25, 73–111.

Rees, A. (1995) The promise of social citizenship. *Policy and Politics* 23, 313–25.

Reich, C. (1964) The new property. *Yale Law Journal* 73, 733–87.

Reynolds, C. (1997) Public health law: Its problems and challenges. *University of New South Wales Law Journal* 20, 576–93.

Rosales, J. (1998) Liberal reformism and democratic citizenship. *Citizenship Studies* 2, 257–72.

Rose, N. (1985) Unreasonable rights: Mental illness and the limits of the law. *Journal of Law and Society* 12, 199–218.

Rothstein, B. (1998) *Just Institutions Matter: The Moral and Political Logic of the Universal Welfare State.* Cambridge University Press, Cambridge.

Rubin, S., Strull, W., Failkow, M., et al. (1994) Increasing the completion of the durable power of attorney for health care: A randomized, controlled study. *JAMA* 271, 209–12.

Sherman, R. (1980) Guardianship: Time for a reassessment. *Fordham Law Review* 49, 350–78.

Simon, W. (1983) Legality, bureaucracy, and class in the welfare system. *Yale Law Journal* 92, 1198–269.

_____. (1986) Rights and redistribution in the welfare system. *Stanford Law Review* 38, 1431–516.

Singer, J. (1992) The privatization of family law. *Wisconsin Law Review* v-vi, 1143–57.

Singer, P. (1995) *From Legislatures to Living Rooms.* Montreal: McGill University, 21 November 1995 [Fourth Annual Labelle Lecture].

Stewart, A. (1995) Two conceptions of citizenship. *British Journal of Sociology* 46, 63–78.

Tesh, S. (1995) Miasma and the "social factors" in disease causality: Lessons from the nineteenth century. *Journal of Health Politics, Policy, and Law* 20, 1001–24.

Uniform Probate Code (1998) National Conference of Commissioners on Uniform State Laws. *Draft Amendments to Uniform Probate Code Article 5 – Guardianship* Meeting, 107th year, Cleveland Ohio, July 24–31, 1998.

Van Gunsteren, H. (1994) Four conceptions of citizenship. *The Condition of Citizenship*. Sage, London: pp. 36–48.

Walby, S. (1995) Gender, work, and post-fordism: The EC context. *International Journal of Sociology* 25, 67–82.

Walzer, M. (1983) *Spheres of Justice: A defence of pluralism and equality.* New York: Basic Books.

Weatherley, R. (1994) From entitlement to contract: Reshaping the welfare state in Australia. *Journal of Sociology and Social Welfare* 21, 153–72.

Wexler, D. (1990) *Therapeutic Jurisprudence: The Law as a Therapeutic Agent.* Carolina Academic Press, Durham, NC.

_____. (1992) Justice, mental health, and therapeutic jurisprudence. *Cleveland State Law Review* 40, 517–26.

Wilson, W. (1994) Citizenship and the inner-city ghetto poor. In B. Van Steenbergen (Ed.), *The Condition of Citizenship*. Sage, London: pp. 49–65.

Yeatman, A. (1995) Interpreting contemporary contractualism. In J. Boston (Ed.) *The State Under Contract, Bridget Williams*, Wellington: pp. 124–39.

ANA MARTA GONZÁLEZ

CHAPTER 13
BIOETHICS BETWEEN NATURE AND CULTURE

A primary concern of practical contemporary philosophy is to discover an ethical rationale which makes possible the justification of determined decisions in the context of a multicultural society eager to respect diversity within a common political frame. Bioethics is a field in which this necessity is perhaps especially pressing. However, the proposals that have been put forth, along the lines of promoting a "minimalist ethics"– be it in principle (Beauchamp and Childress 1994) or in practice (Engelhardt 1986), are open to criticism, and do not appear to be sufficient. I would like to explore another path, more in tune with the ethics of virtue and the classical doctrine of Natural Law. Yet, before doing so, I will expound the reasons that advise against tackling the question of multiculturalism merely from the perspective of minimalist ethics.

HOW CAN ONE EFFECTIVELY RESPECT CULTURAL DIVERSITY WITHIN A COMMON POLITICAL FRAME?

The debate regarding multiculturalism results from the assumption that the presence of diverse cultural communities in the heart of Western societies is a politically relevant fact. For this purpose, it is important to note that the focus of the debate is not merely on the political implications arising from the coexistence of *individuals* from different cultures, because, in that case, we would speak simply of pluralism. Indeed, whenever we speak of "pluralism," we are essentially referring to the fact that at the core of a single society there exist individuals that have different ideas, points of view, or visions of the world. However, the term "multiculturalism" designates something more: not the diversity of individualities as much as the diversity of cultural communities. In turn, Charles Taylor has argued that the special positive evaluation of cultural diversity in practical discourse in recent years reflects our conviction that belonging to a particular community affects one's way of being in the world, and the configuration of individual identities, in a way is qualitatively different to the fact of possessing specific ideas or opinions (1992, 64).

At birth, man receives almost everything from society and culture. His growth and development as a human being takes place in the context defined by a network of human relations, institutions, practices, language, traditions, and values that progressively shape his way of being in the world. Reflection and study help to make conscious, in part, our way of being in the world. The greater part, however, usually remains dormant, structuring one's normal way of understanding reality and explaining it. Often it is the contrast with other ways of being in the world – with other cultures – that sparks the process of reflection and study which makes normal and dormant knowledge become formal in an objective way.

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 173–187.

Indeed, the consideration of culture as a particularly relevant factor in the configuration of one's own identity is one of the fundamental contributions of Romanticism to our culture (Taylor 1993). In this way, Romanticism complemented the abstract defence of equal dignity for all men, handed down by the practical philosophy of the Enlightenment. Certainly, the Romantic tendency to identify political and cultural unity also brought about sharp problems of a political nature. Since the end of the 19th century, these problems have periodically found an echo in the confrontation between socialist internationalism and different nationalist movements: just one of the practical manifestations of the Romantic conflict between universal reason and historical reason.

The conflict in question has taken a new stance in present times. Partly as a natural consequence of the migratory movements coming from other geographic areas, cultural diversity has come to implant itself at the heart of Western societies and it has done so on different terms than before. New cultural communities indeed tend not to claim full integration into Western society, whose values they very often do not completely share. They wish only to enjoy certain, more secure, aspects of Western culture without giving up their traditions or their particular vision of the world (González 1998a). Whether out of recognition that belonging to a concrete cultural group holds a great importance for people, or simply out of respect for the political will of these minorities, or for both of these reasons, practical contemporary philosophy has taken on the challenge of reconciling political unity and cultural diversity. This is the challenge specific to "multiculturalism."

Community and Association. A possible way to confront this question is taking up the distinction between community and association that Tönnies made famous. Accordingly, the term "community", would designate the social form originated in the natural will of men, and the term "association would designate the social forms originated in rational-instrumental will. In this way – writes Tönnies – "community is characterized by social will as harmony, rites, customs, and religion; association through social will in the capacity of conversation, legislation, and public opinion" (1979, 277). Based on a similar distinction, Aristotle's *Politics* is usually regarded as an example of the political communitarian approach, contrasted with the modern one, which is closer to the association model. Certainly, this division calls for further clarification.

According to John Rawls, for example, a well-organised democratic society does not totally adjust to the model of community or to the model of association we have just described. It distinguishes itself from community because it does not assume a shared philosophical, religious, or moral doctrine. It also distinguishes itself from simple rational association for two reasons: firstly because entry into the community takes place at birth and not by personal decision, and secondly because society does not have final objectives and ends in the same sense as associations have (1993, 40–3).

On the other hand, within the Aristotelian approach there is room for a distinction similar to the one noted by Tönnies, a distinction that Hannah Arendt learned to recognise when she contrasted the peculiarity of familiar community with the political community. For Aristotle, indeed, the familiar community consists of natural elements at its basis, and aims at the satisfaction of basic needs of life; by contrast, political community consists of words and actions, and aims at the pursuit of the good life. One can interpret the difference between life and good life as that between living, worrying about what is necessary for life, and living to achieve meaningful purposes. For Aristotle, the *polis* becomes the realm in which man, freed from basic needs, performs noble actions and the heroic deeds of freedom. Hence one understands that in the ancient world, politics could be considered the way of life of the free. Actually, according to Hannah Arendt, the distinction between *public and private* in the classical world pointed at the distinction between the realm of freedom and the realm of the necessary, the latter carrying a certain *deprivation* of recognition and freedom (1958, 61–5).

Yet, the passage into the Modern Age was marked by the transformation of that perception of politics. Certainly, Aristotle's broad conception of politics as the way of life of the free had been lost long before Modernity. Hobbes' reduction of politics to a theory of power and of the State marked an explicit and drastic split with the ancient tradition. Likewise, Modernity was accompanied by a progressive colonisation of the public sphere by the economy, which, for Aristotle, had previously been confined to the domestic sphere. Therefore, the relationship between private and public is inverted. On the one hand, the public space becomes a space for fighting for one's survival; the very emergence of a "political economy" in modern times is significant in this sense. On the other hand, the "good life" is now situated in the private sphere; the social paradigm of ethical life thus moves from the town square and the battlefield to the bourgeois home (Taylor 1989).

THE PRIVATE AND PUBLIC IN THE DEBATE ON MULTICULTURALISM

The debate on multiculturalism rests on a modern understanding of the relationship between the private and the public. Accordingly, the activities that dominate the public realm are generally reduced to transactions of money and power, while the private world is supposed to assume the dimensions that give meaning to life (Llano 1988; 1991). In this sense, and taking into account the reduction of the public sphere to transactions of power and money, a cynical reading of the multicultural problem would sound like this: how does one guarantee that people from distinct cultural communities, maintaining their cultural diversity, have similar political and economic advantages?

To avoid formulating this problem in such terms, we have to realise that political unity also involves a common ethics. Frequently people tend to assume that a common ethics is a threat to cultural diversity. This is why proposals of universal yet minimalist ethics seem so reasonable at first glance, especially if they present themselves as neutral. In this regard, and in the concrete field of bioethics, the case of Engelhardt is paradigmatic. For this author, the mission of bioethics as secular knowledge is to provide a neutral framework for dealing with moral problems in biomedicine, where doctors, nurses, patients, and individuals, in general, maintain diverse moral points of view (1986, 12). According to Engelhardt, such secular bioethics should not accept any concrete vision of a good life, or any particular beliefs about the nature of the good. Rather, it should be an empty and abstract framework, thought up for facing practical problems derived from the coalition of different ethical views (1986, 53). The same could be said of Max Charlesworth's approach, which considers liberal commitment combined with the idea of moral autonomy, and the ethical pluralism arising therefrom, as a "meta-partidist" position (1993, 29).

However, that the ideal of an "empty frame," or, in general, the "ethical minimum," is sufficient to privilege a particular culture over others is something we frequently forget. At the very least, it is a position that is not considered in all its implications. Responsible for this neglect is the fact that the very approach to this problem rests on a mistake about the meaning and scope of the word "culture"; namely, considering that culture can be treated as a private dimension of existence.

In this regard, it seems important to note that what we call "culture" cannot be confined to the sphere of the private because all culture, to the extent to which it is alive, fights to become present in public life. Actually, culture not only claims public recognition but also aspires to configure the same public sphere (Llano 1999). Political grievances of minority groups can be interpreted from this perspective. The proposal of minimalist ethics for the public realm derives from a liberal understanding of the relation between the private and the public sphere (O'Neill 1997, 14–33). In this proposal, it is falsely assumed that a universal formal morality could actually be compatible with the particular ethical views of certain communities, provided that these remain closed to the private sphere.

Yet, if we adopt a practical point of view, that is, the point of view of the agent, one must recognise that a similar double set of morals becomes possible only by making use of a "profound" superficiality. The reason is that such a double standard is incompatible with the unity of practical reason, and also with the dynamism proper to all culture. Indeed, as Ruth Benedict pointed out,

> [O]nce a system of values is accepted and set for living, the individual cannot keep separate for long a parcel of his life, in which he thinks and behaves according to an opposite system of values, without the danger of falling into inefficiency and chaos. Within a society, men try to look for a greater conformity, a justification, and some common motivations. Without this degree of coherence, all the network would crumble (1974, 19).

The deepest factor leading to cultural homogeneity is the unity of practical reason. Because of this unity, human beings living between two cultures cannot artificially sustain the difference between those cultures for long. The appeal to, or the imposition of, minimalist ethics constitutes a sort of artifice, whereby one assumes a vision of the private and the public, not necessarily in agreement with that of cultural minorities. In this sense, the proposal, apparently impartial, of a formal morality for a multicultural society, i.e. a morality which should be superimposed upon the ethics of a particular community, is actually the proposal of a double morality, which contradicts the unity of practical reason, and eventually leads to cultural uniformity.

A NATURAL PATH TO DEFEND CULTURAL DIVERSITY

If we consider cultural diversity in the context of a single society with values worthy of being preserved, the path to take is not the imposition of minimalist ethics; rather the path to defend diversity follows by strengthening cultures from the inside. To a great extent – although not exclusively – such reinforcement is a matter of ethics. Here the word "ethics" means something more than a reasonable alternative to violence (Engelhardt 1986, 39). Ethics, in the sense that we use the term here, refers above all to the intrinsic improvement of man. Such improvement is not as relative as it might appear at first glance. Of course, the diversity of cultures brings with it different standards of what a good man is. Nevertheless, the internal consistency of any culture essentially depends on avoiding contradictions with its natural basis. Just as Spaemann observes, "culture is humanized nature, not abolished nature" (1989, 215; 1991, 245). In those words, the term "nature" could both designate – although in a different sense – much human nature and Nature as a whole, i.e. the natural ecosystem.

For our purposes here, "nature" will merely designate the desiderative dimension implicit in our practical conduct: nature as a desiring principle, as *ôrexis,* as that is how Aristotle uses it in ethical contexts. Accordingly, the human being is taken as a wishful being right from the start. While this is a characteristic common to other natural beings, in humans we find natural tendencies whose satisfaction does not depend simply and plainly on nature. Indeed, unlike what occurs in animals, human tendencies are presented as inconclusive or relatively indeterminate. That relative indetermination can be attributed to the fact that human biology partially reflects a feature of reason – its opening *ad opposita* – a feature that Aristotle poses explicitly in contrast to the determination *ad unum* proper to nature.[1] Now, this "relative indetermination of our biology" explains why the satisfaction of human tendencies cannot take place merely "by nature," but requires the intervention of an instance that is no longer simply natural (in the sense of *ôrexis*) – the *prohairesis*, the *electio*, or choice.[2] Accordingly, Aristotle does not define man simply in function of the appetite, but in function of choice: "Hence choice is either derivative thought or intellectual desire, and such an origin of action is a man" (1925). In his account we notice, very clearly, the practical continuity between nature and reason, or the radically moral dimension of human nature. According to Aristotle, man is the being that lives choosing, not only desiring, but desiring intelligently. Intelligence is certainly necessary because man's tendencies are not integrated in advance; rather, integration is a task entrusted to practical reason, which tries to accomplish this task with a view not merely to survival, but to lead a good life.

Certainly, good life assumes life, and with it the satisfaction of basic needs. Yet, even at this level man behaves differently from animals. The very existence of intelligence allows man to face his biological needs with a view to the future.[3] To that corresponds economy, the art of administering goods. Economy unveils a characteristic of man that is not found in animals; as man, a being, is capable of "having". In the thought of Aristotle, "to have" is a prerogative of human beings; animals, properly speaking do not possess anything. By contrast, man possesses in various ways,[4] through the body, certainly, but also through knowledge and in a very particular way through habits (Polo 1996a). Through the body, indeed, we possess material goods; through knowledge we possess reality in an intentional way; finally, we possess ourselves and the world through habits. In this way we inhabit the world – that is, we create culture.

In fact, if one can define culture as "humanised nature," it is important to point out that the humanisation of nature depends essentially on the development of habits. These, as Aristotle indicates, can be of three types: intellectual, ethical, and technical.[5] The diverse development of these three kinds of habits, allows us to recognise not only what distinguishes a particular culture from others – or the differences that, as Elliot observes, are being noted throughout time in the heart of a same culture[6] – but also the partial superiority – which is never absolute – of some cultures over others. There are cultures superior to others from a technical point of view, and cultures that realise some particular moral values more clearly than others. To the extent that each culture represents a particular and effective way of inhabiting the world, "culture is formally plural, because it is not susceptible to the success, of a definitive culmination" (Polo 1997, 144).

Now, the consistency and perdurability of a culture depends, in great measure, upon the solidity, not only of its institutions but also of the intellectual and moral habits developed by its people. The intellectual habits, indeed, make possible the achievement of a vital synthesis between the old and the new, fostering continuity between progress and tradition. The moral habits, in turn, make possible the integration of scientific and technical knowledge into the practical context of human life. From this perspective it is easy to see that scientific and technical habits should be accompanied by a proportionate ethical growth. Otherwise the integration to which we referred is not possible. Ethical integration, indeed, is a matter of growth, because ethical demands are derived from life, and there is no middle point between growth and decadence (Polo 1996b).

From this perspective, protecting a culture cannot mean anything other than enabling or favouring the growth of the habits of its people. As it has already been said, the development of intellectual habits makes possible the integration of knowledge and technique into the context of practical life. Moral habits, in turn, provide internal consistency to every community. It is evident, indeed, that if the members of a community are united by the ties of justice, solidarity, reciprocal help, loyalty, etc., the internal consistency of that community will be greater. At present, the development of moral habits is, for the most part, the work of individual members of the community. But politics can help to this end, for instance, by protecting the natural foundation, upon which moral habits develop. At this point, an appeal to Natural Law becomes opportune. However, in view of the numerous objections that this doctrine has received throughout the history of ethics, it is necessary to specify which Natural Law we are dealing with.

WHICH NATURAL LAW?

Objections to the doctrine of Natural Law are well known. However, I tend to think that, for one reason or another, the version offered by Thomas Aquinas avoids these objections. I also think that it contains some fruitful insights for the current debate on multiculturalism.

Objections to Natural Law. Some objections to the doctrine of Natural Law point to the very presence of the term "natural" in what is supposed to serve as a moral criterion. In these objections it is assumed that there is a radical separation between the natural and the moral, so that the mere mention of a natural criterion for morality should be immediately rejected as a sort of naturalism. These objections can be traced back, in different ways, to Kant and Moore. Both authors, however, work with a concept of nature previously reduced to its empirical aspects: the concept of nature employed by modern science. Such a concept of nature – ultimately identical to the arguments of Hume – is the result of an abstraction, by reference to which morality could no longer make any reference to natural ends. Instead morality should have to be interpreted in purely formal and prescriptive terms; this is what occurs in Kant (González 1999a) and, in a different way, in Moore (Simpson 1987, 14). Yet, even the appeal to nature as source or criterion of morality, at least as suggested in Thomas Aquinas' work, would not regard nature as such, as the only source or criterion of morality. In general, Aquinas refers to the correct moral behaviour as secundum rationem behaviour. In other words, the direct reference is to reason, not to nature. Of course, Aquinas' practical reason is not pure practical reason; unlike Kant's practical reason, Aquinas' takes into account some previous conceptions of the good, ultimately rooted in our human *nature*.

Objections to Natural Law are also frequently nourished by the confusion that surrounds this, when not merely a name to designate each one's deepest moral convictions (Hare 1993, 120), is taken to be a term susceptible to many meanings, none of which would justify the supposed normative character of nature. Hume's objections develop along these lines (1967, 475). John Stuart Mill, for his part, rejects the normative meaning of nature arguing that it would be incompatible with human creativity; he also points out that accepting nature as moral criteria would be an invitation to immorality rather than to morality (1969, 401–2). Moore expresses himself in similar terms.[7] Finally, John Dewey also adds to the line of objections by considering the appeal to nature as a moral criterion incompatible with the possibility of social change (1988, 258).

Now, those objections assume a consideration of nature, which does not succeed in recognising the peculiarities of human nature, implied in the concept of a "rational nature". To affirm that human nature is rational, indeed, does not only mean that man is endowed with reason, but – just as we noted earlier – that his very biology is radically affected by the essential characteristic of rationality; the opening *ad opposita*. Among other things, this means that, in the strictest sense, man does not possess instincts, but rather inclinations. The difference between an instinct and an inclination lies precisely in the fact that the culmination of the first occurs by nature, whereas, in the second case an act of freedom is needed. On the other hand, it is evident that the harmony between inclinations is not guaranteed by nature. For this reason man has to learn to lead his life. Human life does not culminate biologically but, rather, by its very nature, it requires a moral continuation. Neither creativity nor the possibility of social change is put in jeopardy.

Finally, another group of objections point at the metaphysical and theological assumptions of this doctrine. Those assumptions, it is argued, would impede the recognition of nature as a moral criterion by those not sharing them. This is, for example, the objection of Engelhardt (1986, 37), and could also well be that of Rorty (1991, 15) or of Habermas (1992, 24; 1998, 71), with their reiterated appeals to post metaphysical thought. In regards to this I would like to underline that Aquinas's Natural Law certainly has a metaphysical foundation. However, his thought on Natural Law designates, more than anything else, the natural way of reasoning on practical matters; a way of reasoning based upon the very structure of our practical reason.

Natural Law and Practical Reason. Martin Rhonheimer has thus argued that Natural Law is the law of all practical reason (1987; 1994a). For the purpose of understanding the reach that this expression has for our topic, it is necessary to show its connection with nature and habits as noted above. In this regard, it is fit to recall a key distinction between classical practical reason in contrast with modern practical reason – both in its Kantian and in its utilitarian version – namely, its connection with nature. This connection is evident in the case of Aristotle, at least if we look deeply into the concept of virtue, and it is also found in Aquinas, although with an important difference which I will point out later.

The connection of practical reason and nature in the case of Aristotle is an essential one. We could even say that without a reference to nature there is no practical reason for Aristotle: this can be shown by putting some texts together. After having referred to the different types of life, Aristotle writes in Chapter 7 of his first book of *Nichomachean Ethics,* "there remains, then, an active life of the element that has a rational principle (of this, one part has such a principle in the sense of being obedient to one, the other in the sense of possessing one and exercising thought)."[8] Further on, in Chapter 13, speaking on the parts of the soul, he writes:

> Therefore the irrational element also appears to be two-fold. For the vegetative element in no way shares in a rational principle, but the appetitive and in general the desiring element in a sense shares in it, in so far as it listens to and obeys it; this is the sense in which we speak of paying heed to one's father or one's friends, not that in which we speak of 'accounting' for a mathematical property. That the irrational element is in some sense persuaded by a rational principle is indicated also by the giving of advice and by all reproof and exhortation. And if this element also must be said to have a rational principle, that which has a rational principle (as well as that which has not) will be twofold, one subdivision having it in the strict sense and in itself, and the other having tendency to obey as one does one's father.[9]

Now, the comparison of both texts allows us to distinguish practical reason and theoretical reason. While the latter "thinks and considers", the former tries to persuade the desiderative part of the soul. This desiderative part of the soul is included in the concept of nature. Keeping in mind the distinction between theoretical and practical reason, Aristotle introduces that between intellectual and moral virtues:

> Virtue too is distinguished into kinds in accordance with this difference; for we say that some of the virtues are intellectual and others moral, philosophic wisdom and understanding and practical wisdom being intellectual, liberality and temperance moral. For in speaking about a man's character we do not say that he is wise or has understanding but that he is good-tempered or temperate; yet we praise the wise man also with respect to his state of mind; and of states of mind we call those which merit praise excellences (virtues).[10]

The connection between practical reason and nature as *ôrexis* is essential for a full understanding of Aristotle's concept of moral virtue. If we now remember the intrinsic connection that, according to Aristotle, exists between prudence and moral virtue, we will have the basic elements for understanding, in their just terms, the

Thomist doctrine of Natural Law. Let us pause for a few moments, however, to examine the connection between moral virtue and prudence.

In Chapter 12 of Book VI, devoted generically to the study of intellectual habits, Aristotle observes: “Again, the work of man is achieved only in accordance with practical wisdom (prudence) as well as with moral virtue; for virtue makes the aim right, and practical wisdom makes us take the right means.”[11] Now, the “means” that bring about the end, are not simply things but actions.[12] For this reason it is not strange that, not much later, Aristotle also observes that “virtue makes choice right,”[13] since without choice no action can take place. On this point he warns that prudence is inseparable from moral virtue, although prudence also implies a certain ability: “there is a faculty (aptitude) which is called cleverness, and this is such as to be able to do the things that tend towards the mark we have set before ourselves, and to hit it” – and he concludes: “Practical wisdom (prudence) is not the faculty, but it does not exist without this faculty.”[14] Yet, what we need to underline here is that there is not prudence without moral virtue, so that “it is not possible to be good in the strict sense without practical wisdom (without being prudent), nor practically wise without moral virtue.”[15]

At the same time, Aristotle maintains with equal firmness that moral virtue cannot exist without prudence. The circularity that we detect here, characteristic of practical matters, is appeased in large part by the difference that Aristotle introduces between natural virtue and moral virtue. According to Aristotle, natural virtue is a disposition in agreement with prudence (*phronesis, prudentia*); whatever disposition is natural to a certain class of good deeds. Moral virtue, by contrast, is not only a disposition agreeing with right reason, but “the state that implies the presence of right reason,” that is prudence.[16] Prudence, for its part, is responsible for discerning in practice, which are the virtues that must be put into effect in any given moment (González 1998b, C. 3). Thus, the difference between a person with many natural virtues yet without prudence, and a person with few natural virtues yet possessing prudence (and therefore with moral virtue) is that the second possesses the fundamental rectitude that permits, first of all, to not act against virtues, and secondly, to try to get them all, in spite of the fact that he may not possess excellent natural dispositions for a certain class of good works. To review those concepts of Aristotelian ethics it is important to understand the Thomist doctrine of Natural Law and the words of Aquinas when, in the context of an article about Natural Law, he observes that “law is something of reason.”[17] This affirmation is crucial in order to understand the mark of a conception that is essentially, and without prejudice of other influences, a deepening in Aristotle’s doctrine on practical reason (Rhonheimer 1994b). We need to underline this point because it is precisely the practical character of the law that got lost in the Renaissance versions of this doctrine and even in modern moral philosophy until Kant (Finnis 1980).

Kant, in effect, is responsible for the recovery of practical reason for modern moral thought. But, as it has already been pointed out, he understands practical reason without any reference to nature; his is a purely formal practical reason. This purely formal practical reason is precisely at the origin of the dialectic between universal reason and historical reason that has occupied moral philosophy since then. In this regard, it seems to me that the only way to overcome this dialectic involves recovering the reference to nature and habits in the sense that I have pointed out. In addition, with this reference to nature and habits in mind, we may be able to root ethics back in culture, without losing sight of the universality of morals.

Natural Law and Multiculturalism. Aquinas certainly assumes Aristotle's legacy, although he does not do so without personal discernment, thereby recognising the deficiencies of the Aristotelian approach. Likewise, he takes into account the Stoic contribution of a universal morality, also underlined by Christianity. Now, what interests us here is not so much the origin of these ideas, as their explicative capacity and their possible validity for our present situation, in which we must aim for a synthesis of a universal morality and respect for cultural diversity. The synthesis in question will necessarily be different from the one achieved by Aquinas in his own times. However, essential philosophical intuitions, as those that underlie the problem of the "One" and "Many", remain the same. This is what we should appreciate in his doctrine of Natural Law.

In effect, if we understand in depth the nature of practical reason we will understand that there are many possible morals – not because each culture has its own but, rather, because each man has his own. By "morals", in this context, I do not mean a code of universal norms but *the practical itinerary of each man*. To understand morals as an itinerary it is necessary to adopt a practical point of view – that is, the point of view of the human agent who finds himself living and acting.

From this point of view, one can say that each man faces his life in a conscious search, at times more intense than others. The search in question may be less dramatic if it is carried out from the heart of a tradition, instead of being carried out along its margins. The reason is that every tradition can be regarded as an accumulated wisdom that has shown itself to be efficient throughout a long or short period of time. Yet, even within a tradition, every person has to find his own path.

Now, if morality has any connection with real life, it cannot be understood apart from that existential search. Furthermore, the intrinsically moral character of human life is particularly manifested in the search itself. The search is perceived as the principal moral task; thus, an abandonment of the search would be perceived as a failure or an existential crisis (González 1999b). Accordingly, just as each man is confronted with the task of living, he is also confronted with a moral task; and the way he deals with this task is to be perfected and corrected through life's itinerary (Inciarte 1973, 203).

To understand morality in these terms requires, in my opinion, a deep understanding of the nature of practical reason. I consider that the moral thought of Aquinas assumes this type of rationality. At this point, however, someone could certainly ask: "where is the presumed universality of morals here?" The answer to this question is implied in the previous paragraph. I understand, in effect, that the universality of morals is to be found in the criterion we use to correct our actions. Such criterion is not an oracle. It is a habit; the habit of the first practical principles, also called *synderesis.* According to Aquinas, *synderesis* is in charge of remedying the indetermination *ad opposita* characteristic of reason.[18]

The way in which this habit becomes operative in practice can be compared to the way the habit of first speculative principles operates. Indeed, as we are able to detect contradictions in our reasoning and speech, so we are also able to detect practical contradictions when we take action. "Practical contradictions" is an expression I use here to refer to all ways of action that enter into contradiction with the very principles of human life, that is, of moral life.

These principles, in that they are not the ends of different virtues, are the contents of the *synderesis,* qualified, not in vain, by Aquinas as *semina virtutum* (sower of virtues). Of such ends we have knowledge thanks to *synderesis*. Certainly, due to erroneous ideas or acquired vices, such knowledge can also be darkened in practice. However, Aquinas underlines that the habit of *synderesis* never entirely disappears.[19] At the same time, the practical knowledge it provides can be reinforced; it is reinforced, in fact, as long as moral virtue is consolidated in us.

Upon affirming that the universal dimension of morality lies in the ends of virtues, it could appear that we have not reached much farther than Aristotle. This is not so. What is true, rather, is that the introduction of the *synderesis,* as an intellectual habit in charge of prescribing to prudence the ends of the virtues, means that, right at the very beginning of ethics, there is an intellectual principle. This aspect was not as clear in Aristotle. Yet, it is precisely the introduction of such an intellectual principle at the very roots of ethical thinking that makes possible the constitution of ethics in a practical science (Wieland 1981). This should allow Aquinas to enter into dialogue with modern ethics more easily than Aristotle. Such a dialogue would likewise be facilitated by the more normative tone buried in his appeal to the law as a first principle.

Yet, while it is true that what this law prescribes is the action in agreement with virtues, it is likewise true that any virtue has then a natural basis. This natural basis is disclosed by Aquinas when he points to the existence of some universal precepts which incorporate the tangential structure of our nature. [20] It is from this perspective that one can best interpret the reference to the natural inclinations in the classical place in which Aquinas refers to Natural Law.

> The first principle in the practical reason is one founded on the notion of good, viz., that good is which all things seek after. Hence, this is the first precept of law: that good is to be done and ensued, and evil is to be avoided. All other precepts of natural law are based upon this: so that whatever the practical reason naturally apprehends as man's good (or evil) belongs to the precepts of the natural law as something to be done or avoided. Since, however, good has the nature of an end, and evil, the nature of a contrary, hence it is that all those things to which man has a natural inclination, are naturally apprehended by reason as being good, and consequently as objects of pursuit, and their contraries as evil, and objects of avoidance. Wherefore according to the order of natural inclinations, is the order of the precepts of the natural law ...[21]

Aquinas goes on to note, firstly, the inclination toward life from which those precepts ordered to protect life might be inferred. Secondly, Aquinas mentions the inclination to procreation and the education of children, etc., in conformity with which there would be other precepts directed toward the protection of those goods. Finally, he refers to the inclination to know the truth, both in theory and in practice, thereby assuming the conditions of social life. Thus, in agreement with this inclination, there would be another series of precepts oriented to the protection of the search for truth. As long as such a search has a place in the heart of society, there would also be room for precepts which protect and promote the goods of peace and justice.

It is true, nevertheless, that although we are capable of understanding the goodness of such precepts when they are enunciated in a universal way, their meaning can be hidden from us whenever we descend to a specific situation. Aquinas, as it is known, did consider the possibility that moral knowledge can be darkened in determined historical moments due to human weakness and corruption. He used Caesar's *War of the Galias* as an example. In that work, namely, Caesar recounts how the Germans had come to regard robbery –which contradicts Natural Law – as something permissible.[22] We could also assume that our culture presents some points of confusion, if not blindness, when appraising the morality of actions that, in a manifest way, contradict the good noted in each one of the specific natural inclinations.

It is evident indeed, that during the last century, our culture has accumulated numerous exceptions to each one of those precepts, giving ample room to the current debates in bioethics. For example: the first kind of precepts is widely questioned in the debate over abortion and euthanasia; the second even more so because it directly refers to the core of sexual morality; finally, the third hardly finds an echo in a world that has decided to pact with theoretical and moral relativism as a way of life.

This is not the place to enter into these debates. Here I just note that they constitute a clear sign that Western culture has been defining itself for some time by its progressive estrangement from nature (Alter 1991) in the assumption that this estrangement redounds to a greater freedom for man (Spaemann 1978; 1983). The thesis of ethical liberalism, indeed, is that there are no intrinsically evil modes of action, i.e. actions evil by their own nature.[23]

In this regard, a pertinent question – in continuity with the thought of Hans Jonas (1998) – would be this: are we really in the condition of guaranteeing the continuity of our culture appealing to reason untied from nature? Is it really possible to exist completely without the meaning noted in our natural inclinations, at the time of, for example, social organisation? Until now, ethical liberalism believes in facing the challenges by complicating legal machinery, or confining indefinitely its solution to technique. Nevertheless, reflection is necessary.

As noted earlier, moral liberalism consists of the idea that reason, untied from nature, favours greater freedom for man. Yet, is this really so? Does it not rather constitute a utopian pretension? Has our "freedom from nature" become so extreme? Could it not rather occur that nature treated in this way will turn against us? Does Western culture weaken nature while others prepare to take hold of its reins?

Despite its quite "apocalyptic" tone, the last possibility should not be worrisome by itself. After all, throughout history, cultures have inherited from one another, not necessarily due to greater technical or military power, but because of intrinsic debilitation. Now, the estrangement from nature could have this effect. After all, man depends on nature, in one way or another. I understand that this is not a conservative thesis; it is not meant to criticise reform, social change, or progress. However, there are reasons to think that preserving the natural basis of our actions is the only way in which progress and social change can be beneficial to man. In the end, man cannot completely free himself from nature. If nature is not incorporated into his moral judgement he will have to confront it by technical means. But technique cannot solve everything. At the individual level, for instance, it is clear that technique alone cannot solve the internal integration of tendencies. There is no technical substitute for virtue, nor a utilitarian substitute for truth.

Certainly, a moral and perfectionist argument like the one I have just presented is not an immediate political argument. However, morals and politics have in common, each in their own way, the end proper to practical reason: the affirmation of man. In the case of morals, affirmation of man is direct and directly entrusted to the individual who, upon acting, looks out for his own good. This good, if it is to be called so, cannot be equated with individual interest, but must remain open to the common good. Indeed, from a moral point of view, the good of the individual is inseparable from the process of learning to see the common good as part of one's own good.

From a political point of view, however, the affirmation of man can only be indirect, since a true affirmation of man cannot take place without his co-operation or freedom. Accordingly, the maximum to which political action can aspire is to create favourable conditions so that man can affirm himself. Now, to the extent that we recognise that man is not an amorphous subject, we should take his nature into account. Human nature can be realised in a number of cultures. That is why in protecting human nature we are setting the basis for the protection, not of a particular culture – the liberal culture – but rather of every possible culture.

NOTES

1. Aristotle, Metaphysics, IX, 2, 1046 b 5–7; 17–24.
2. Ibid: IX, 5, 1048 a 3–11.
3. Aristotle, On the soul, III, 10, 433 b 9–10.
4. Aristotle, Categories, III, 15; Metaphysics V, 23.
5. Aristotle, Nicomachean Ethics, I, 13; VI.
6. "…The most important question that we can ask, is whether there is any permanent standard, by which we can compare one civilization with another, and by which we can make some guess at the improvement or decline of our own. We have to admit, in comparing one civilization with another, and in comparing the different stages of our own, that no one society and no one age of it realize all the values of civilization. Not all of these values may be compatible with each other: what is at least as certain is that in realizing some we lose the appreciation of others. Nevertheless, we can distinguish between higher and lower cultures; we can distinguish between advance and retrogression" (Elliot 1948, 18).
7. Moore, G.E., Principia Ethica, § 28.
8. Aristotle, NE, I, 7, 1098, a 3–5.
9. Aristotle, NE, I, 13, 1102 b 29–1103 a 3.
10. Aristotle, NE, I, 13, 1103 a 3–10.
11. Aristotle, NE, VI, 12, 1144 a 6–7.
12. In this sense, what Aristotle could say really is that "good deed is an end in and of itself." NE, VI, 5, 1140 b 7.
13. Aristotle, NE, VI, 12, 1144 a 20.
14. Aristotle, NE, VI, 12, 1144 a 23–29.
15. Aristotle, NE, VI, 13, 1144 b 30.
16. Aristotle, NE, VI, 13, 1144 b 26–28.
17. Thomas Aquinas, S. Th. I–IIae, q. 91, a. 2, ad. 3. Where he proposes his general definition of law as aliquid rationis, in S. Th. I–IIae, q. 90, a. 1, sol.
18. Thomas Aquinas, De Veritate, q. 16, a. 2, ad 4.
19. Thomas Aquinas, De Veritate, q. 16, a. 3.
20. Such precepts are not formal. Synderesis is a universal precept, but not formal: "good must be done, evil must be avoided." Simply put it is a precept that requires being concrete. According to Aquinas, the immediate concretisation of that precept remits to the content of natural inclinations, whose ends

constitute the first goods known by practical intellect. Intellect knows the ends of inclinations, that is, the goods to which these assign themselves. Among them, figure the very good of reason, that is, truth, as a good, which must be sought; not only theoretical truth, but also practical truth, that is, the truth of action. That is why intellect knows not but the goods of each one of the inclinations, but rather it knows them under the different ways in which such goods must be pursued in order to constitute human good in an integrated way. One must not forget that synderesis prescribes the search for the practical good, rather than an arbitrary search for isolated goods. Practical good is the good, which is within hand's reach, the good of concrete action, in which multiple aspects if a rational mode are integrated. These modes are, precisely, virtues. For that reason Aquinas can say that synderesis is the "sewer of virtues."

[21.] Thomas Aquinas, S. Th. I–IIae, q. 94, a. 2, sol.

[22.] Thomas Aquinas, S. Th. I–Iliad, q. 94, a. 4, sol.

[23.] This position considers that only intention or consequences turn an action bad. In other words: the end sought or the predictable effects of our actions facing the achievement of greater well-being would be the only elements to keep in our ethical judgments. Certainly, at the heart of a multicultural society, not even that solution would appear sufficient. In the view of the moral conflicts posed by persons proceeding from different moral communities, it would be important in the last instance to appeal to consensus.

REFERENCES

Alter, G. (1991) *Naturvergessenheit. Grundlagen einr umfassenden Bioethik*, Wissenschaftliche Buchgesellschaft, Darmstadt.

Arendt, H. (1958) *The Human Condition*, University of Chicago Press, Chicago, 61–5.

Aristotle. (1925) *The Works of Aristotle*, ed. W.D. Ross, Oxford, Clarendon Press, vol. IX.

Beauchamp, T., Childress, J. (1994) *Principles of Biomedical Ethics*, 4th Ed., Oxford University Press, New York.

Benedict, R. (1974) *El crisantemo y la espada. Patrones de cultura japonesa*, Alianza Editorial, Madrid.

Charlesworth, M. (1993) *La bioética en una sociedad liberal*, Cambridge University Press, Cambridge.

Dewey, J. (1988) "Contrary to human nature," *The Later Works*, 1939–1941, vol. 14, Southern Illinois University Press, Carbondale, IL, 258–61.

Elliot, T.S. (1948) *Notes Toward the Definition of Culture*, Faber and Faber, London.

Engelhardt, H.T., Jr. (1986) *The Foundations of Bioethics,* Oxford University Press, New York.

Finnis, J. (1980) *Natural Law, Natural Rights*, Oxford University Press, New York.

González, A.M. (1998a) "El compromiso multicultural," *Nuestro Tiempo*, September.

_____. (1998b) *Moral, Razón y Naturaleza. Una investigación sobre Tomás de Aquino*, Eunsa, Pamplona.

_____. (1999a) *El Faktum de la razón: la solución kantiana al problem de la fundamentación de la moral*, Caudernos del Anuario Filosófico, Pamplona.

_____. (1999b) "Expertos en sobrevivir: Binx, Bascombe y otros," in *Expertos en Sobrevivir. Ensayos ético-políticos*, Eunsa, Pamplona.

Habermas, J. (1992) *Faktizität und Geltung. Beiträge zur Diskurstheorie des Rechts und des demokratischen Rechtsstaats*, Suhrkamp, Frankfurt am Main.

_____. (1998) *Facticidad y Validez. Sobre el derecho y el Estado democrático de derecho en términos de teoría del discurso*, Trotta, Valladolid.

Hare, R.M. (1993) *Essays on Bioethics*, Clarendon Press, Oxford.

Hume, D.A. (1967) *A Treatise of Human Nature*, III, I, Clarendon Press, Oxford.

Inciarte, F. (1973) Ética y Política en la Filosofía Práctica, in *El reto del positivismo lógico*, Rialp, Madrid.

Jonas, H. (1998) *Das Prinzip Verantwortung. Versuch einer Ethik für die technologische Zivilisation*, Insel Verlag.

Llano, A. (1988) *La nueva sensibilidad*, Espasa Calpe, Madrid.

_____. (1991) *The new sensibility*, Servicio de Publicaciones de la Universidad de Navarra, Pamplona.

_____. (1999) *El humanismo cívico*, Ariel, Barcelona.

Mill, J. S. (1969) "Nature," in *Three Essays on Ethics, Religion and Society*, ed. J.M. Robson, Routledge & Kegan Paul, London.

O'Neill, S. (1997) *Impartiality in context. Grounding Justice in a Pluralist World*, State University of New York Press, Albany, 14–33.

Polo, L. (1996a) "Tener y dar," in *La existencia cristiana*, Eunsa, Pamplona.

_____. (1996b) *Ética: hacia una versión moderna de los temas clásicos*, Aedos, Madrid.

_____. (1997) *Presente y futuro del hombre*, Rialp, Madrid.

Rawls, J. (1993) *Political Liberalism*, Columbia University Press, New York.

Rhonheimer, M. (1987) *Natur als Grundlage der Moral. Die personale Strucktur des Naturgesetzes bei Thomas von Aquin: eine Auseinandersetzung mit autonomer und teleologischer Ethik*, Tyrolia Verlag, Innsbruck-Wien.

_____. (1994a) *La prospettiva della morale. Fondamenti dell'etica filosofica*, Armando Editore, Roma.

_____. (1994b) *Praktische Vernunft und die Vernünftigkeit der Praxis. Handlungstheorie bei Thomas von Aquin in their Entsteehung aus dem Problemkontext der aristotelischen Ethik*, Akademie Verlag, Berlin.

Rorty, R. (1991) *Contingencia, ironía y solidaridad*, Paidós, Barcelona.

Simpson, P. (1987) *Goodness and Nature. A defense of ethical naturalism*, Martinus Nijhoff, Dordrecht, Boston, Lancaster.

Spaemann, R. (1978) "Naturaleza," in Conceptos fundamentales de Filosofía, Krings & Baumgartner & Wild (eds.), Herder, Barcelona, 619–33.

_____. (1983) "Nature", in *Philosophische Essays,* Stuttgart, Reclam, 19–40.

_____. (1989) *Glück und Wohlwollen*, Klett-Cotta, Stuttgart.

_____. (1991) *Felicidad y Benevolencia*, Rialp, Madrid.

Taylor, C. (1989) *Sources of the Self. The making of the Modern Identity*, Cambridge University Press, Cambridge.

_____. (1992) "The Politics of Recognition," in *Multiculturalism and 'The Politics of Recognition,'* Princeton University Press, Princeton, NJ.

_____. (1993) *Hegel and the Modern Society*, Cambridge University Press, Cambridge.

Tönnies, F. (1979) *Gemeinschaft und Gesellschaft. Grundbegriffe der reinen Soziologie*, 8 Auf., Leipzig, 1935. *Comunidad y asociación*, ed. Península, Barcelona.

Wieland, G. (1981) *Ethica: Scientia Practica. Die Anfänge der Philosophichen Ethik im 13.* Jahrhundert, Münster, Aschendorf.

HENK JOCHEMSEN

CHAPTER 14
MEDICAL PRACTICE AS THE PRIMARY CONTEXT FOR MEDICAL ETHICS

INTRODUCTION

"We must rethink the very project of bioethics" (Engelhardt, Jr. 1996, 340). With these words Tristam Engelhardt, Jr. closes his article on theory and methods in a post-Christian, post-modern age. Before reaching this conclusion he argues that the theory of secular bioethics "provides the deconstruction of any canonical content, thus rendering secular bioethics either a content-less ethics directed to methods... or a cluster of competing moral visions" (1996, 339). Not an attractive alternative for any academic discipline. In the latter case we will find forcefully endorsed convictions and intuitions without a supporting foundation, rendering these convictions and intuitions mere taboos, according to Engelhardt. He himself seems to opt for the first alternative: a morality without moral content, focusing on procedures of consent. Though having no specific moral content, such a morality, according to Engelhardt, has the moral implication that it determines as wrong any imposition of a particular morality on the unconsenting innocent.[1]

Consequent (moral) pluralism is in my opinion neither a theoretical nor a practical possibility. It requires that everybody accept pluralism and thus rules out the option of not accepting pluralism. It ultimately leads to a form of oppression and thus contradicts itself. As human beings we seem to be sentenced to take a position on what we see as the good life, whenever we speak on what ought or ought not to be done. Every attempt to take a neutral observer's position can ultimately be exposed as just another position.

This is not feasible in practice because social structures and institutions embody a particular morality. Society is not a kind of morally neutral arena where everyone can independently pursue personal self-realisation. This is especially clear in medicine. Leaving the choice to the patient, in fact, means presenting certain alternatives to the patient that medicine has developed but that embody particular moralities (e.g. in case of male infertility, using ICSI or KID, or accepting not having one's "own" child; Finkenstein 1990, 13–16). An ethic concentrating on patient consent tends to forget to question the alternatives that are offered.[2] Patient autonomy can become an inroad for the technological imperative ("what can be done, should be done"). Therefore, for different reasons, neither of the two alternatives presented by Engelhardt seems to be acceptable. Where do we go from here?

The indicated processes in bioethics of secularisation, pluralism, and concentration on abstract principles, especially on patient autonomy and consent, led

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 189–204.

some of us related to the Prof. Lindeboom Institute in the beginning of the 1990s to consider precisely that question: where do we go from here?[3] This chapter presents central elements of the way we have tried to respond to the dilemma described so well by Engelhardt. On the basis of a summary of our evaluation of the situation in the field of medical ethics some characteristics of a fruitful medical ethics will be identified. It will then be argued that the concept of practice put forward by MacIntyre (1981), but elaborated in a specific way using the work of the Dutch philosopher Dooyeweerd, offers a good starting point for a medical ethics that fulfils those characteristics (Dooyeweerd, 1953–1958). The model of medical practice that will be presented may provide a piece of common ground for moral deliberation that will save it from a conflict of mere taboos, while leaving enough space for an ongoing debate on a content-full ethics relevant for today's medicine.

WHICH DIRECTION?

Our evaluation of mainstream medical ethics can be summarised as follows:

1. To a great extent it consists of applying general abstract principles to medical practice. The specific nature of that practice is not sufficiently taken into account. Such an approach betrays a specific understanding of the relationship between theory and practice. This approach can be called the subsumption theoretical approach. In this context it can be rendered as follows: (1) the rationality of ethical decision making is determined by the degree to which it is guided by general ethical principles; (2) the practical effectiveness of the results of such decision making is guaranteed by framing the medical ethical dilemma in terms of these same principles; (3) and by separating these principles from any particular worldview or religion in order to make them universally applicable.
2. It does not recognise that the content of those principles depends upon one's world-view or basic belief system. In fact, a kind of moral philosophy has been encouraged (if not required, if one wanted to be heard in public) that, as Callahan phrases it, "Aspires simultaneously to a kind of detached neutrality and a culture-free rationalistic universalism" (Callahan 1990, 4). Such an approach clearly leaves little space for world view and religion, and as a consequence bypasses the positions and intuitions of real people who always have specific beliefs.
3. Whereas medical ethics, until the 1960s, mainly was an ethics of and for physicians, containing a codification of medicine and of the medical profession, mainstream medical ethics now has become a patients' ethics concentrating on patients' rights and patient autonomy. However, it continues to think in terms of an opposition between physician and patient, thus neglecting the specific nature of medical care and its core relationship, i.e. the patient-physician relation. This relation, like other institutionalised social relations, is not accidental to human existence; these relations form the very substance of life. Human life without such structural relationships is unthinkable.
4. It tends to *react* to problems presented by medicine, often as a result of medical technical advances. As a result ethics generally "runs behind" and tends, at its best, to regulate or normalise a practice that seems to develop autonomously but embodies a morality that is not seriously questioned.

This diagnosis prompted us to try to formulate a medical ethics that seriously considers these criticisms. It should, therefore: (a) take into account the specific nature of the *medical situation*; (b) as well as its specific relationship, the physician-patient relation, at the same time taking seriously (post) modern aspirations to freedom of choice; (c) formulate a view on the medical enterprise itself and particularly on the place of technology in medical practice; and (d) take into account the role of basic beliefs with respect to, e.g., the meaning of life, illness, and death, avoiding at the same time that such convictions become mere taboos in the ethical debate.

It is not possible in this chapter to formulate a medical ethics that fulfils all of these requirements, even if it were possible to do so. Here we would like to make an important step toward the formulation of such an ethics by presenting an ethically relevant analysis of medicine. For ethics to seriously consider the medical situation and, in particular, the patient-physician relationship, it should analyse the structure of this situation and its core relationship. This is what will be presented here in a deductive manner. I postulate that medicine can be analysed fruitfully in terms of a social practice and will then give that analysis. Subsequently, I will argue that this analysis is suited to medicine and has important normative implications for it.

AN ANALYSIS OF MEDICINE

Medicine as Practice. We consider medicine as a social practice, in which the concept of practice is characterised by the following three elements.[4]

1. A practice is a coherent form of *socially established human activity*. This means that the practice exists before the individual practitioner enters the practice. A practice like medicine has developed by a long historical process and is the result of many decisions and processes that embody normative choices. In this sense medicine is in itself already a normative practice. The individual practitioner is introduced into the practice as a certain way of doing certain things. The practice shapes the behaviour of the practitioners before an individual practitioner can begin to shape the practice. An implication of this view is that the understanding of medical care as the voluntary relation between two free rational agents rests on an abstraction. (Which does not deny that certain choices are left open to both the practitioner and the patient).
2. Secondly, a practice has a certain *finality* and the activities of which a practice consists are directed at the realisation of this finality. It is important to distinguish this finality from goals that individual practitioners may have. Goals set by individual or collective actors in medical practice do not necessarily contribute to the realisation of the finality of medical practice. Somebody may become a physician to make money, but trying to realise this goal does not necessarily serve the optimal realisation of medicine. The finality belongs to the very nature of the practice and is not founded in the intention of the practitioner.[5] The finality of medical practice allows for a number of subjective goals of physicians and patients, but at the same time limits the range of goals and the methods utilised to attain them that are appropriate for that practice (as will be illustrated below).

3. The third essential element of a practice is that human activities in a practice are seen as *rule-guided behaviour* in which the “rules of play” are understood as the standards of excellence for the practice. These standards or rules define excellent practice and at the same time provide criteria to evaluate the activities of individual practitioners. When the rules of the practice are well observed, the finality of the practice is being realized.[6] A practitioner who is able to practice in accordance with the rules is a competent practitioner. In short: practising is competent performance. In this context, the concept of “rule” does not so much refer to rules in the sense of “knowing that,” which implies the ability to formulate the applied rules. Rather, it refers to rules in the sense of “knowing how,” which is an intuitive awareness of rules, consisting in the ability to act according to a rule and to assess the correctness of this application. One can easily see that performing a practice, e.g. playing the violin or practicing medicine, cannot be learned just by theoretical instruction about the practice. Engaging in that practice is indispensable. Thus, a competence exists in the ability to act according to the (usually implicit) rules of the particular practice. These rules have an intrinsic normative nature in the sense that they describe competent practicing and enable the assessment of the actions performed within practices. This is a second way in which a social practice, as meant here, is a normative practice.

In short, we see medicine as a normative practice, understood as a coherent form of human activity that is governed by (mostly implicit) rules. These rules relate to the internal nature and finality of the practice and define the competence and the standards of adequate performance of that practice. Rules that make a practice recognisable as a specific practice are called “constitutive rules.”

Finality. Having laid out the main structure of medical practice as an example of normative social practice, two major questions remain: (a) what is the finality of medical practice; and b) how can we identify the constitutive rules of a normative practice in general and of medical practice, in particular.

We attempt to answer the first question through a hermeneutic-ethical approach to medical practice. This involves a description and interpretation of medicine in which the normativity embodied in its practice is made explicit and elucidated. We take our starting point in what the Dutch physician G.A. Lindeboom called “the core medical situation”:

> The core medical situation is where a sick person asks help from a physician as someone, whom he believes, is able and willing to give it (Strijbos 1992, 121, 122).[7]

To take this core medical situation as our starting point involves a normative choice. It implies that, in our opinion, medicine as a normative practice should be understood on the basis of this core of the patient-physician relationship. As a consequence we choose not to trace the norms for the patient-physician relationship on the basis of an analysis of the health care system. In other words, we choose to analyse medicine and heath care as a whole on the basis of the micro level and not to define the micro level on the basis of an analysis of the macro level.

What does Lindeboom's description of the core medical situation teach us about the finality of medical practice and about its constitutive rules? The "core medical situation" consists of three elements: (1) the appeal of the suffering patient or his complaint; (2) the special competence of the physician; and (3) the professional character of medical practice.

The latter element is the basis for the former two. A profession can be described as a "body of persons engaged in a calling" in which the calling can be formulated as "the rendering of a public service" (Unschuld 1978, 519–520).[8] The oath or promise that professionals usually swear before they begin to practice their profession should be seen in this context. This pledge has to make clear to the (potential) patient/client that the professional will use his specialised knowledge and skills (the second element) in the best interest of the patient/client (the first element).[9] This guarantee of the trustworthiness of the professionals is required because they deal with vital interests of their patients/clients who cannot themselves control whether the professional activity is in their best interests, due to its specialised character. To maintain the confidence of the population, the profession clearly needs to control the quality of the service rendered by the individual members and to be willing to render accounts of their activities and policy to society at large.[10]

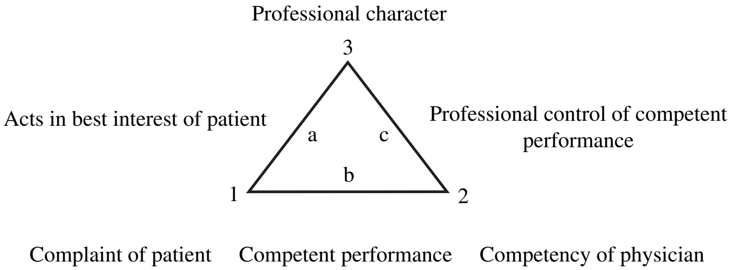
From the three elements of the core medical situation we conclude that the patient-physician relationship is essentially a relationship of assistance and care that aims at serving the health of the patient. This means that the finality of medical practice can be indicated by "care", which is both a principle and a good. We understand care as "a normative attitude which regards the well-being of others as intrinsically valuable" (Puolimatka 1989, 144).[11]

Constitutive Side. I come now to the second question posed at the beginning of this section. How can we identify the constitutive rules of medical practice and how are they related to its finality? At this point we draw upon the philosophy of Dooyeweerd that distinguishes in reality a number of so-called modal aspects (Dooyeweerd 1958, Vol. III). An "aspect" is understood as an irreducible mode of human experience that at the same time constitutes a way of evaluating human activity. Every aspect can be typified by a central idea that at the same time is a normative principle. And in every practice, being a coherent form of human activity, those "aspects" can be distinguished. This means that the way a person performs a practice can be evaluated from a logical-analytical, social, economic, juridical, aesthetic, and ethical point of view, among others. The evaluation from any of these perspectives requires principles and rules as criteria. The principles to be used in this way are the normative principles related to the various modal aspects mentioned above. These normative principles can be elaborated in more concrete rules. All these principles and rules together can be identified with the previously mentioned constitutive rules of medical practice. In other words, the constitutive rules (mainly of the "knowing how" type) that define an adequate performance of a practice can be derived from the normative principles of the modal aspects in which a practice functions.

Medical Situation: Sick Person Asks Physician for Help

Three Elements Can Be Distinguished

1. Complaint of patient
2. Competency of physician
3. Professional character-oath or promise



a: qualifying constitutive rules; derived from the normative principle of the qualifying aspect: care/benevolence.

b: interpretation and observance of founding and conditioning constitutive rules: medical-technical, economical, juridical, etc.

c: medical-professional standard and mutual control of quality of performance of individual professional that should take place.

Figure 1. Schematic Representation of the main elements of medical practice

All practices function in all aspects, but the aspect-related rules do not apply to all practices in the same way. Three kinds of constitutive rules can be distinguished, namely qualifying, founding, and conditioning constitutive rules. The qualifying rules are derived from the normative principle of the aspect that gives a particular practice its own typical character. We call this the typical or qualifying aspect that is directly related to the finality of the particular practice. It can easily be seen, for example, that the practice of a musician is aesthetically qualified and the practice of a manager of a company, economically. The rules related to the qualifying aspect of a particular practice are the constitutive rules in a typical or qualifying sense. The finality of medical practice is "care," which at the same time is the normative principle of the ethical aspect (see note 11). So, the ethical aspect is qualifying for medical practice or, put differently, medical practice is ethically qualified. This means that its performance is guided by the normative principle of the ethical aspect, "care".

The founding constitutive rules are the rules that prescribe the activities characteristic of a specific practice. In a sense, the practice is founded in that aspect.

In the next section we will argue that for medicine, as well as for other practices of assistance, the technical aspect is the founding aspect.

The other aspects, like the social, the economic and the juridical, are conditioning aspects from which the conditioning constitutive rules are derived. These rules formulate conditions that should be observed in performing a practice, but they neither define the "technicalities" of the practice, nor its finality. The compliance of the founding and conditioning rules should be guided by "care", the normative principle of the qualifying aspect.

An adequate, competent performance of a practice requires the *simultaneous realisation of all the constitutive rules*. In an assessment of the way in which a certain practitioner performs his practice, those constitutive rules function as *norms*.

Using this analysis all social practices can be described as a specific constellation of constitutive rules that are characteristic for that practice.

Regulative Side. Before we explain the implications of this analysis one more element should be added. The constitutive aspect of a practice concerns the normative constitutive rules that should guide the performance of the practice and provide the norms required to assess that performance. However, any performance and assessment involves a specific *interpretation* of the rules.[12] In other words, the performance of a practice is always realised from a wider interpretative framework on the meaning of that practice for human life and for society and, hence, on the *direction* performances of that practice should take. Put more generally, human behaviour, as well as (theoretical) reflection on it, is regulated by world view. This also applies to ideas about the adequate performance of medical practice. The (constitutive) structure does not determine the direction of the performance, like the rules of a play do not determine the course of an actual play, but only which courses are correct. The course of actual performances is also determined by what we call the regulative side of practices. At this level world views have a regulating function; depending upon their view of the meaning and the coherence of reality, people act differently. In medical practice, regulative ideas of both physicians and patients about health, sickness, medicine, the good life, etc., will influence the way in which the constitutive rules are applied.

Often the regulative ideas or conceptions in medical practice remain quite implicit. Currently ideas that transcend the positive knowledge of the sciences and humanities have lost their legitimacy in public debate. World views and religious beliefs are usually seen today as subjective perspectives which cannot be rationally justified. But the fact that it is impossible to give a scientific justification of our fundamental beliefs and convictions does not mean that they are unimportant. In our post-modern culture, in contrast to pre-modern cultures, medicine is no longer seen as embedded in a metaphysical or religious world view and hence, will be threatened by unrealistic expectations. Science and technology have become their own regulative framework. This is why science and technology can play a seemingly autonomous role in medical practice. An ethic that does not want to react post fact to technological developments should give a structural place to ideas pertaining to the regulative side and thus create a starting point for a constructive debate on these ideas and their impact on medical practice. This will be discussed further in the next section.

IMPLICATIONS OF THE ANALYSIS

What are the implications of this structural analysis for medicine? It was concluded that medicine is ethically qualified. What does this mean? Medicine is foremost a response to human fragility and vulnerability as manifested in diseases, handicaps, pain, and death. It aims at helping people who are in trouble, due to physical or mental suffering. Medical activities bear the stamp of assisting people, caring for those whose existence is threatened by physical or mental disorder. The character of medicine is in the first instance defined by the existence of illness and the act of a specific kind of care that aims at dealing with the threatening disorder. As a consequence medicine has, or at least should have, its own finality and nature: serving the health interests in its own specific way, defined by its constitutive rules.[13]

The conclusion that medicine is ethically qualified also means that the ethical way of assessing medical practice regulates the ways of assessment corresponding with the other constitutive rules. The implication of this will be explained when discussing other kinds of constitutive rules.

1. Founding constitutive rules

Why did we call the technical rules the founding constitutive rules of medical practice and what are their implications?

The Greek of antiquity called the practice of a physician *technèe iatrikèe. Technèe* indicates a combination of knowledge and ability to bring about something. *Technèe* is closer to what we call a craft than to modern technology. It is theory-guided action, where theory is not yet to be understood as modern theoretical scientific knowledge, but rather as a practical, empirical "know how." (Cf. Schipperges 1978, 460). The history of medicine in the Western civilisation tradition has been understood as a specific kind of action that is directed at bringing about a particular state of affairs, in which it is assumed that there is some kind of empirical, intelligible relation between the action and its effect. Action in this context should be understood in a broad way; it includes all activities of the physician exercised in the context of the treatment of the patient, including the consult. Because of its empirical character, medical *technèe* cannot be learned apart from engaging in medical practice. However, when medicine, in the course of the 19th century, increasingly became more influenced by modern science, the character of the "theory" that guided action in medical practice changed. Modern science, by definition, is abstract and general. Technology based upon science tries to find or develop the most effective means to realise general goals, like building bridges, making MRI scanners, constructing instruments for micro-surgery, etc. This description makes it clear that in our view, medicine should not be understood solely as a science or a technology.[14]

This is an important observation. Modern specialised medicine has a highly technical character; its technology has developed on the basis of medical science. But medicine is not just an application of scientific knowledge or of technique, but a practice that is founded in medical technology and technique which in turn is founded in the practice of medical science.[15] In trying to help a patient, a physician should draw upon his scientific knowledge and technical skills. However, the possible contribution of any form of technique in dealing with the health problem of the patient should determine whether that technique in fact is employed. This seems self-evident, but that is not always the case in practice. There is always the temptation to use a technique simply because it is available and it may confirm an already established diagnosis or – in a fee-for-service system – it may, among other things, be to the physicians' financial advantage or may reassure an uncertain patient. Today's curative medicine is strongly technology-driven. In our culture, with its strong emphasis on health and its high expectations of medicine, there is a real danger that the professionalism of physicians will be judged solely according to their competence and ability to use medical technology. In this view the technical aspect, with (biomedical) effectiveness as its normative principle, would become the qualifying aspect of medicine. At this point the physician tends to become a medical engineer who applies medical techniques to patients at their or their relatives' request. However, the request may well spring from an overestimation of technology, from a misunderstanding of the burdens and benefits of the treatment or from the very offer of the physician. This is a perversion of the normative structure of medicine that will be detrimental to patients (Brennan et al. 1991; Leope et al. 1991). The normative analysis indicates that the use of techniques should be guided by the principle of care; not the mere physiological effectiveness, but the medical beneficence should be the criterion for its use, granted the patient's consent.

That the technical aspect is the founding aspect of medical practice implies, secondly, that any medical intervention should be grounded in the technical and scientific rules of medicine. This means that a medical intervention needs a justification by a medical-professional indication (Miller 1993). Referring to the request of the patient is not a sufficient ground for an intervention, though it is a necessary condition.[16] So, the medical scientific and technical rules do not just give medical care its specific contents, they also limit medical practice. It is evident that the care of a physician for a patient differs from the care of a geriatric helper for a senior citizen. The care of a physician for his patient gets its character from the medical field of competence. This is a limited field even though it is not possible to define sharp limits and the field develops and changes in the course of history. The physician does not deal professionally with whatever problem in whatever way (Jochemsen et al. 1995). He deals in a specific way with disruptions in the physical or mental aspect of normal life. The difference between caring practices, which are all characterised by the same constellation of constitutive rules, resides primarily in different contents of the scientific and technical rules in which those practices are founded.

2. Conditioning Constitutive Rules

Competent performance of medical practice not only requires compliance with the ethical and technical rules, but also with the so-called conditioning constitutive rules. Of these, the social, economic, and juridical are most important. Because of the focus of this book on the principle of autonomy, we will concentrate here on the juridical rules. This pertains to the sphere of law and legality. The normative principle of this modal aspect is justice, primarily in the sense of retributive justice. It aims at the maintenance of established rights and duties. In as far as distributive justice is established by law, compliance with retributive justice requires, also, distributive justice. One of the main points in modern patient law is the respect for patient autonomy or self-determination. Justice requires the observance of respect for patient autonomy and the rule of informed consent that has been derived from it. However, in itself this principle, understood as simple self-determination, has no limits. Can the direct interests of other individuals only rightly limit it, or do other interpretations and related limitations of this principle concord better with medical practice? This is an important question in bioethics that I want to elaborate in this section.

The above model can help in finding an answer. But before using this model, it should be remembered that the emphasis on patients' rights resulted not only from the general emancipation of citizens, but also from a struggle for power about the ever-increasing medical technological possibilities. Because of their invasiveness, and their advantages and disadvantages, the patients no longer accepted that only physicians would decide on their use (Reich 1996). Medicine has become too powerful to leave it to physicians. The over-estimation in our society of science and technology has led to a euphoria with (medical) technology that in too many situations did not really benefit the patient (Barsky 1988; Kassirer 1989; Cassell 1993). Although we have no definite proof, I presume that patients' rights have been formulated as a means to resist and master medical power. In medical ethics this led to the shift from physicians' ethics to patients' ethics. A shift, however, that did not root ethics once again in a concept of the medical relation, but in an erroneous use of medical power. As a reaction to this, the emphasis on patient autonomy had a salutary influence. To achieve optimal freedom of choice with respect to medical treatment and to recover responsibility for one's own body and health is of great value. But though salutary as a reaction, this emphasis on patient autonomy is not a healthy basis for a new medical ethics. First of all, because in and of itself it is an atomising principle, positing people as individuals against each other, whereas, as we saw, medicine is essentially a relational activity.

We realise that nowadays there is a lot of elective medical treatment in which the patient role practically disappears behind the client role. Nevertheless, the major part of medical care deals with people whose life or existence is threatened by a physical or mental problem. Many of them are not (fully) competent when a decision should be made concerning their medical treatment. To a certain extent this can be repaired by measures like proxy consent and advanced directives. Yet, an autonomy-based ethics pushes too much of medical care to the margin of "exceptions to the rule."

Second, even for fully competent people, a fully autonomy-driven ethics contains tensions, if not contradictions. It would imply that people are treated *because* they demand it. Physicians would become mere medical technicians who could only object to a certain treatment, even if clearly disproportional from a professional point of view, for conscientious reasons. And in the long run, perhaps not even for these reasons, could one expect compliance with patients demands from a physician, which would ultimately frustrate the autonomy of the physicians. But even so, patients/clients would be dependent upon medicine and have to put themselves into the hands of those "medical technicians" and trust them. Not only that they will technically do a good job, but also that in case of complications, unexpected findings, etc., they will decide for the "best of the patient." This requires a medical-professional judgement.

Not all situations can be foreseen by an advanced directive and these must always be interpreted (Howsepian 1998). Furthermore, in our present society with its high estimation of health and medicine, for certain people the only limit to the use of medicine would be technical possibility and (private) affordability. But the slew of new technologies unavoidably has a social effect: it shapes social relationships and institutions in a way that will affect other people, also those who are opposed to that technology, for instance, by confronting them with choices that they do not want to make (Finkenstein 1990; Silver 1997).[17] So giving way to the autonomy of some will lead to an effect on the autonomy of others. It can be argued that a society that has individual autonomy as its highest value runs the danger of developing into a society dominated by the powerful. In other words, by those who best succeed in realising their autonomy.

Viewed this way, autonomy, in its ultimate consequence, turns out to be the very opposite of what medicine has historically pursued: care for the sick and vulnerable. Few would argue, theoretically, for such a dominance of respect for autonomy. But if no viable and convincing alternative model is put forward and institutionalised, health care may develop that way in practice.

The conclusion of the above is not that patient autonomy should not have a proper place in medicine and medical ethics. It is not only unthinkable, but also undesirable that the place obtained by personal responsibility and freedom of choice (informed consent) in health care should be given up. But what is their proper place? Again we draw upon the Dooyeweerdian philosophy of the modal aspects. The various aspects are not just coordinate but should be seen in a certain hierarchical order. The sequence of the aspects relevant for our purposes is as follows: technical, social, economic, juridical, ethical. In this sequence a higher aspect is founded in the lower aspect, which in turn is opened up by the higher aspect.[18] The aspects are irreducible: each aspect represents a novelty that opens up the lower aspect to a further realisation. This also applies to the juridical and ethical aspects. These do not contradict each other. The juridical founds the ethical, the ethical leads the juridical to its finality. Retribution that is made an absolute and not guided by care becomes harsh and ceases to be justice. But care that is not supported by laws, regulations, procedures, and institutions that embody them, will be too weak and wavering to achieve its purpose (Benner 1998).

What does this mean for our reflection on autonomy? Autonomy and care should not be set over against each other. Neither are they inseparable in health care. Autonomy made an absolute undermines the very core of health care and medicine. Respect for autonomy should be guided and opened up by care, which in medicine receives its practical content from the scientific and technical rules. On the other hand, patient autonomy as established in patients' rights provides a structure on which the practice of care can be built. We recall that according to the normative model, competent practice of medicine requires the simultaneous realisation of all the constitutive rules. So, requests of patients must be respected, but within the space of responsible professional medicine that aims at serving the health interests of the patients. Autonomy is first of all a strong defence right; people should not be treated against their wish. However, autonomy is only a claim right within the limits of the medical-professional standard, upheld by legal protection, and, in practice, also within the financial limits of either insurance or the individual patient.

This brings us to another point with respect to autonomy. The commercialisation of health care that is taking place, especially in the USA, is partly a consequence of the 'technificalisation' and 'juridicalisation' of medicine When medical care becomes the delivery of a medical technical service at the demand of buyers, these buyers, understood as those who pay, will try to buy the products with the best price-quality ratio. The overestimation of medical technology and the juridicalisation resulting in liability claims and in stressing individual autonomy, have made medicine unnecessarily expensive. Organisational structures and financing systems have been established that try to canalise and constrain health care expenses. These new institutions, of which managed care organisations are a well-known example, deal with health care delivery as an economic activity. This clearly contrasts with the normative structure of medical practice as presented above, leading to a number of ethical problems (Polder et al. 1997).

3. Regulative Side

In the former section we have used expressions like "medical professional standard," "responsible medical professional care," and "health interests." These terms unavoidably entail a value judgement with respect to their content. This is precisely the reason why Engelhardt and others do not limit medical care by this kind of notion, but leave it to the individual patient (Engelhardt 1996). This leads to the supremacy of autonomy and reduces ethics essentially to a set of decision-making procedures. However, this is also a choice ultimately determined by a substantial world view. We have argued above that this choice has a number of negative implications for health care, as it does not do justice to its normative structure. Analysis of this structure also indicated that a social practice like medicine has a regulative side. This refers, among others, to ideas and opinions on health, and on the proper task of medicine. Any realisation of a practice involves at least an implicit choice on such issues. It is impossible not to choose with respect to the regulative side as it belongs to the very character of a normative practice and can only be opened up by ideas and convictions pertaining to that regulative side. In our society people have different and even contrasting views on those points. But in a democratic society this should not lead to a ban on bringing those views up for public debate, which results in the imposition of a certain view on the public sphere. It should lead to the creation of institutions and procedures for public debate in which everybody's views can be expressed and weighed. When decisions have to be made in view of legislation, a majority will ultimately decide. But a majority should take into account, as much as possible, minorities with diverging views. And while a majority decision should, in principle, be respected by everybody, it does not mean that the debate must end. In a dynamic society, changes in the predominant ideas pertaining to the regulative side of medical practice will always occur. An intelligent exchange of ideas and experiences, as well as the demonstration of models of care in which certain convictions with respect to health, illness, death, and medicine are lived out (hospice care being an illustrative example), can influence this process.

CONCLUSION: TOWARD RETHINKING BIOETHICS

In the introduction to this chapter, I concluded that the predominant form of bioethics demonstrates serious flaws. A different approach is needed that will (a) take into account the particular character of the medical situation, as well as, (b) its core relationship, the patient-physician relationship and the role of patient autonomy, (c) indicate the role of medical technology in medical care, and (d) give account of the meaning that religious and world view convictions have for medicine.

In the quest for such an approach I have analysed medicine as a normative practice. The resulting model deals with the elements just mentioned and, therefore, seems to be a good basis for further rethinking ethics. The normative model of medical practice is only the beginning of a different way of doing bioethics. It presents a normative, but formal, structure for practicing medicine. That structure indicates the various types of rules that should be observed in medical practice and their mutual hierarchical relationship. It does not define the content of those rules. This would be the task of a substantial content-full ethics. Here, once more, religious and world view convictions will play an important role, and debate will be part of the practice of doing bioethics. But precisely because our normative model is a formal model, it could form a fruitful basis for attempts to formulate a more content based ethics. Though it is evident that the model itself embodies some normative choices, especially with respect to the hierarchical relationship between the aspects and their normative principles, the model allows for a large diversity of performances of medical practice. This means that it could be applied in different health institutions. The most important features of the model are that medicine is considered a practice with a single finality, furthering the health interest of the patient, to be pursued by a simultaneous realisation of hierarchically ordered rules. This normative structure protects medical practice from being reduced to medical technology as a mere instrument to achieve the subjective goals of physician and patient. Modern medicine has become both technically and symbolically so powerful that allowing such use would make unacceptable victims.

NOTES

[1] E.g. Daniel Callahan (1990, 4): “Yet that pluralism becomes a form of oppression if, in its very name, we are told to shut up in public about our private lives and beliefs...”

[2] Callahan rightly points out that a great failure of predominant secular bioethics is its enormous reluctance to question the conventional ends and goals of medicine; Callahan, ibid.

[3] In the context of a research project carried out on behalf of the Dutch Ministry of Health on cost control in health care and professional autonomy that resulted in a Dutch report. Some of the results are published in Polder, et al. (1997), Jochemsen & Ten Have (2000), Polder & Jochemsen (2000), Hoogland & Jochemsen (2000).

[4] This analysis of social practice has been inspired by A. MacIntyre’s definition of practice which runs as follows: “By a `practice’ I am going to mean any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended”, (MacIntyre 1981, 175). We realise that MacIntyre’s use of this concept has been disputed seriously (see Horton & Mendus 1994). However, we elaborate this concept in a different way using other philosophical concepts.

[5] For the difference between goal and finality (or destination) see: Dooyeweerd 1958, vol. III, 570, 571.

[6] For example, the finality of the practice of a musician, good music-making, is realised when the musician performs according to the “rules of the art.”

[7] This same approach to medicine is taken by several others in the field of (the philosophy and ethics of) medicine; see Pellegrino & Thomasma 1988, esp. p. 6, 32 and 54 where A. Jonsen & A. Jameton are quoted who support the same model; see also Orr 1998, 162.

[8] Unschuld concludes that the central meaning of the concept of profession is the pursuit of the selfless rendering of a public service and the independence in practicing the work typical for the particular profession. See also lemma `profession’ in Webster’s third new international dictionary.

[9] This ethical commitment of the medical profession is also formulated in medical ethical codes. For instance the *Declaration of Geneva* of the World Medical Association states: “The health of my patient will be my first consideration” and the *Declaration of Helsinki* says in its introduction: “It is the mission of the medical doctor to safeguard the health of the people”.

[10] See Koehn 1994 (68) who argues that the oath or pledge is the ground of a profession; “... professionals’ unilateral, unqualified pledge to serve a specific end of a particular group of vulnerable human beings grounds professionals’ authority...”.

[11] This is the description of Puolimatka for benevolence. However, benevolence can be described as `wishing the good of others’, without referring to any specific action. Other authors take beneficence as the central principle of medicine (e.g. Pellegrino & Thomasma, 1988). But this principle understood as `doing good to others’, does not involve the intention of the actor. With the word benevolence Puolimatka indicates both the intention and the action directed at the good of others. We also want to keep together the intention and the action, and to avoid misunderstanding we use the word `care’ to indicate that attitude, instead of benevolence. We agree with Puolimatka that care, understood as the normative attitude that regards the well-being of others as intrinsically valuable, is also an adequate description of the core principle of the sphere of morality (see further in the text).

[12] The interpretation of a piece of music depends also upon the ideas of the performer on the way the piece should be understood and performed.

[13] For example, nursing also serves the health interest of patients, but in an other way, defined by its own specific constitutive rules.

[14] The German author G. Rager (1991, 75–85) distinguishes between theoretical sciences, applied sciences and practical sciences. The second can be equated with technology but should be distinguished from practical science that requires resolution and discernment to be able to act correctly in the individual case; see also: Delkeskamp-Hayes 1993, 271–319.

[15] Cf.:"The necessary integration of a differentiated body of knowledge and skills into the practical unity of treatment and healing cannot emerge from that powerful force of knowing and acting that modern science cultivates in a methodologically precise manner"; (Gadamer 1996, 35.)

[16] That in many situations, the patient's condition and complaint allow for a range of further examinations or even interventions and the patient's request may have a significant influence on the exact decision of the physician, does not change this. When asked, the physician should always be able to give a medical justification for any medical action.

[17] In this context one may think for example of reproductive and genetic technologies; cf. Silver (1997), who argues that the development and unavoidable use of reproductive technology may in the long run even lead to the generation of different species of humans.

[18] By way of explanation, an analogy can be drawn with a systems-theoretical approach to living organisms. In the simplest living organisms, the bacteria, at least two system levels can be distinguished: a physico-chemical and a biotic level. The latter level is founded in the former and brings the former to its finality, because there is no organism without molecules, but the large biomolecules like proteins and DNA are only produced by living organisms and derive their meaning from their function in those organisms.

REFERENCES

Barsky, A.J. (1988) The paradox of health, *New England Journal of Medicine* 318 (7), 414–8.

Benner, P. (1998) When health care becomes a commodity: the need for compassionate strangers, in Kilner, J.F., Orr, R.D., Shelly, J.A. (eds.), *The changing face of health care*, Eerdmans/ Paternoster Press, Grand Rapids, 119–35.

Brennan, T.A. et al. (1991) Incidence of adverse events and negligence in hospitalized patients. Results of the Harvard Medical Practice study I. *New England journal of medicine* 324, 370–6.

Callahan, D. (1990) Religion and the secularization of bioethics, *Hastings Center report* 20 (4), special supplement, 2–4.

Cassell, E.J. (1993) The sorcerer's broom. Medicine's rampant technology, *Hasting Center report* 23 (6), 32–9.

Delkeskamp-Hayes, C. (1993) Is medicine special, and if so, what follows? An attempt at rational reconstruction, in Delkeskamp-Hayes, C., Gardell Cutter, M.A. (eds.), *Science, technology, and the art of medicine. European-American dialogues* (PM 44). Dordrecht: Kluwer Academic Publishers, Dordrecht, 271–319.

Dooyeweerd, H. (1958) *A new critique of theoretical thought*, The Presbyterian and Reformed Publishing Company, Amsterdam/Philadelphia.

Engelhardt, Jr., H.T. (1996) Bioethics reconsidered: Theory and Method in a Post-Christian, Post-Modern Age, *Kennedy Institute of Ethics Journal* 6 (4), 336–41.

Finkenstein, J.L. (1990) Biomedicine and technocratic power, *Hastings Center Report* 20 (4), 13–6.

Gadamer, H.-G. (1996) *The enigma of health. The art of healing in a scientific age*, Stanford University Press, Stanford.

Hoogland, J., Jochemsen, H. (2000) Professional autonomy and the normative structure of medical practice, *Theoretical Medicine and Bioethics* 21 (5), 457–75.

Horton, J., Mendus, S. (eds.) (1994) *After MacIntyre*, Polity Press (Blackwell), Cambridge.

Howsepian, A.A. (1998) Are advanced directives an advance? *Ethics & Medicine* 14 (2), 34–41.

Jochemsen, H., Strijbos, S., Hoogland, J. (1995) The medical profession in modern society: The importance of defining limits, in Kilner, J.F., Cameron, N.M. de S., Schiedermacher, D.L. (eds.), *Bioethics and the future of medicine: a Christian appraisal.* Eerdmans, Grand Rapids, 14–29.

Jochemsen, H., Ten Have, H. (2000) The autonomy of the health profession: an introduction, *Theoretical Medicine and Bioethics* 21(5), 405–8.

Kassirer, J. (1989) Our stubborn quest for diagnostic certainty. A cause of excessive testing, *New England journal of medicine* 320, 1489–91.

Koehn, D. (1994) *The ground of professional ethics*, Routledge, London/New York.

Leope, L.L. et al. (1991) The nature of adverse events in hospitalized patients. Results of the Harvard medical practice study II, *New England journal of medicine* 324, 377–84.

MacIntyre, A. (1981) *After virtue. A study in moral theory,* Duckworth, London., 2nd ed.

Miller, F.G. (1993) The concept of medically indicated treatment, *J Med Phil* 18, 91–8.

Orr, R.D. (1998) Hippocrates meets managed care: a study of contemporary oath-taking, in Kilner, J.F., Orr, R.D., Shelly, J.A. (eds.), *The changing face of health care*, Eerdmans, Grand Rapids.

Pellegrino, E.D., Thomasma, D.C. (1988) *For the patient's good*, Oxford University Press, New York/Oxford.

Polder, J.J., Jochemsen, H. (2000) Professional autonomy in the healthcare system, *Theoretical Medicine and Bioethics* 21 (5), 477–91.

Polder, J.J., Hoogland, J., Jochemsen, H., Strijbos, S. (1997) Profession, practice and profits: Competition in the health care system, *Syst. Res. Behav. Sci.* 14, 409–21.

Puolimatka, T. (1989) *Moral realism and justification*, Suomalainen Tiedeakatemia, Helsinki.

Rager, G. (1991) Medizin als praktische Wissenschaft, *Arzt und Christ* 37 (2), 75–85.

Reich, W.T. (1996) Revisiting the launching of the Kennedy Institute: re-visioning the origins of bioethics, *Kennedy Institute of Ethics Journal* 6(4), 323–7.

Silver, L. (1997) *Remaking Eden. Cloning and beyond in a brave new world*, Avon Books, New York.

Strijbos, S. (ed.) (1992) *De medische ethiek in de branding – Een keuze uit het werk van Gerrit Arie Lindeboom*, Buijten & Schipperheijn, Amsterdam.

Schipperges, H. (1978) Motivation und Legitimation des Arztliches Handelns, in Schipperges, H., Zeitler, E., Unschuld, P.U. (eds.), *Krankheit, Heilkunst, Heilung.* Alber, Freiburg/München.

Unschuld, P.U. (1978) Professionalisierung und ihre Folgen, in Schipperges, H., Seidler, E., Unschuld, P.U. (eds), *Krankheit, Heilkunst, Heilung*, Alber, Freiburg/München.

ANDRÉS OLLERO

CHAPTER 15

EUTHANASIA AND MULTICULTURALISM

Law, Morals and Religion Within a Pluralist Society

Europe is living a novel experience. Until recently, the call for consensus was generally made within a homogeneous cultural framework, consolidated over centuries. Nowadays however, a genuine search for consensus would oblige us to depart from a completely new, multicultural perspective.

The progressive political reconciliation of the 'two Europes', previously separated by the Cold War, cannot mask the cultural changes that have taken place. Berlin, a city that is still made up of two societies, is a living example of those changes. However, this is a minor problem, compared with the challenge posed by the recent introduction and subsequent settlement of minorities in Western Europe, which supposes a break with the previous racial, religious and cultural homogeneity. This situation has given rise to innumerable problems, for which no solutions have yet to be found.

We will approach the philosophical and legal dimensions of this question from the point of view of anthropological and religious discrepancies, as they have been manifested in recent polemics. The issue of euthanasia will serve as our point of departure.

SEVEN ARGUMENTS IN FAVOUR OF THE DECRIMINALIZATION OF EUTHANASIA

The arguments most frequently brandished in favour of the decriminalization of euthanasia have philosophical and juridical relevance for the emerging multicultural society of Western Europe. The following are some of the most common arguments:

1. The Law, in its function of regulating the public sphere, does not have to incorporate moral demands, however legitimate these may be within the sphere of private self-determination.
2. This is especially true if these moral demands emanate from religious codes, given the requirement of freedom of conscience in a pluralist and secular society.
3. Therefore, we cannot resort to the law to impose our own convictions on others, for instance, by forcing people to suffer beyond endurance. This would be particularly applicable in cases of passive euthanasia, which only aim at alleviating the patients' pain, though they may indirectly shorten their life as well.
4. Rather than repressing freedom by law, we ought to promote those social conditions that would dissuade us from abusing our freedom.

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 205–214.

5. Each person must be free to develop their personality, and ultimately this could even lead to the recognition of a right to die.

6. Although we generally consider the right to life "irrenouncable", the protection of life guaranteed by Article 15 of the Spanish Constitution in fact only applies to those cases where certain minimum levels of quality of life, dictated by human dignity itself, are reached.

7. In all events, the State must exercise a neutral form of restraint in controversial moral debates, to guarantee a greater freedom for its citizens.

By replying to these arguments, we might arrive at some of the responses that this new multicultural society demands.

1. A Law Without Morals? The Law, in particular criminal law, is forced to incorporate certain moral demands. However, this does not mean it has to include them all. The ethical aspirations of the law are limited to guaranteeing a reasonable framework for coexistence, whereas morals encourage us to more fully give meaning to our personal existence. Therefore, we would have to situate the point at which demands, moral as well as other, ought to be incorporated into the law, within this tension between legal boundaries that liberate us from the pressure of minimal ethical principles, and the maximalist tendencies of personal morals. The principle of minimum criminal intervention, representative of the minimalist tendency of the law and reflected in the particular penalising effect of this part of legislation, calls for the penalization of a limited number of behaviours: mainly those that can affect public goods. Therefore – and on moral grounds as well – they should not be left to the discretion of private persons, nor should they be considered sufficiently well-protected by sanctions that do not include the privation of primary goods, such as freedom or, in some countries, even life. Throughout history, people have tried to clarify this close relationship between law and morals; a relationship that is particularly complex when moral imperatives are culturally linked to some religious framework. A happy solution – of misleading simplicity – would be the unrestricted display of moral convictions in the private sphere, combined with their drastic exclusion from the public sphere. This solution would invite people to worship their own gods at home, while desisting from parading them around the streets. However, there will always be people – as any self-respecting inhabitant of Seville will testify – who cannot conceive a public freedom without religious processions. The extrapolation of the model of a multicultural society is perplexing. Each person would live at home in his or her own culture, while the street would be culturally "neutral." We only have to recall the multilingual ups and downs of many culturally homogeneous European societies, to become profoundly sceptical of this proposal. It becomes evident that we cannot determine whether a question is to be regulated by the public mechanisms of law, or ought to be relegated to the private sphere of moral demands – in other words, that we cannot draw the line between law and morals – without the prior and paradoxical adoption of a radically moral judgement. We can only solve this problem by departing from a specific conception of human beings and their relationship with society. For example, from an individualist perspective it would be easy to decide that nobody should be obliged to live even one second longer than he or she wishes. However, from a solidarity point of view, nobody is more altruistic than the fire-fighter, risking his or her life to try and stop someone from committing suicide. The privatization of life, which would free it from juridical restraints and leave it to mere individual self-determination, would simply imply a public moral choice, as debatable as any other.

2. Civil Religion for a Secularized Society The most controversial issues of our post-ideological societies are often attributed to the determination of the "religious element", as to make it felt in the public sphere. Dworkin's approach to "life's dominion" is a good example.

The adoption of a multicultural perspective, which allows us to put religious factors theoretically between brackets, reveals the lack of neutrality in secularization and its scant respect for that freedom of conscience that characterizes the European cultural heritage. No attempt to relegate foreign cultures to the ghetto could avoid being condemned as xenophobic. Any attempt at dismantling the religious elements of each culture, and thus erasing all tension from the public sphere, would be equivalent to converting Tyrians and Trojans to a novel kind of civil religion.

Let us go back to the borderline, where moral and legal concerns overlap. When there are reasons to consider a particular good worthy of legal protection, due to its public importance, the religious significance it has for different social groups should not be taken into account. Otherwise, people might opt for a 'religious' adoption of secularism, which would lead to a generalized war of religions, as a paradoxical tribute to freedom of conscience. Such "neutrality" was put forward by Marx who, in his treatment of the "Jewish Question", lamented the fact that religious freedom was being offered to those who ought to be freed from religion instead (1970 vol.1, 369).The moral judgements that euthanasia requires can be more or less conditioned by religious beliefs. Defending penalization, invoking the argument of authority, would be as absurd as forcing legalization, for the sake of freedom of conscience.

Establishing the limits of the law is still peremptory. Anarchist utopia aside, the boundless manifestation of individual conscience tends to make social coexistence impossible. It is precisely to redress this situation that moral codes and legislation exist. Similarly, an extreme conception of multiculturalism would not work either. The old notion of "public order", or the latest one of "the demands of a democratic society", would hardly be compatible with polygamy and definitely incompatible with human sacrifice.

3. The Moral Defusing of Language As we have already pointed out, criminal law always enforces particular convictions. In fact, it would be inconceivable for criminal law to do otherwise. It would be as absurd, from the point of view of its objective, to impose a penal sanction without being convinced that the protected good deserves protection, as to leave compliance with its norms to the discretion of each subject.

Given this situation, the search for neutrality often takes the form of word games. Thus, the phrases *abortion* and *interruption of pregnancy*, or *euthanasia* and *cooperation in a desired suicide* do not sound the same. In this list of euphemisms we could include the call for "passive *euthanasia*", responsible for causing important ambiguities. When passive euthanasia is confused with the renunciation of indefensible "therapeutic cruelty", it helps us to take for granted the existence of what is redundantly called "*good euthanasia*", which would stop this term from being considered absolutely rejectable. However, the proper use of this term would signify the "provocation of death by withholding necessary aid". An example can be found in the German practice of "*premature euthanasia*", which means that newborn babies with malformations are not fed.

The use of this type of coded language does not favour multiculturalism; on the contrary, it renders communication difficult by creating an artificial sub-cultural space that silences dissenting voices.

4. The Promotional Function of Penal Rules It is not wise to create a dichotomy between *repressing* certain behaviours and *promoting* the social conditions that would reduce the possibilities of such behaviours actually taking place. Criminal law does not only repress, but also has "pedagogical" relevance, as it acts directly to promote or dissuade certain conducts. Citizens tend to consider those actions forbidden by law as "bad", and those permitted by law as "good", or at least acceptable. Although every act of decriminalization seems to constitute a step towards greater freedom, at the same time it tends to constitute a particularly effective way of promoting social conditions favourable to the multiplication of previously reprehensible behaviours.

However many proposals in favour of decriminalizing euthanasia are only trying to find solutions for exceptional cases, worthy of our compassion, they cannot help but give rise to "normalising" consequences. Thus in our collective consciousness, the heroic fire fighter, ready to prevent an imminent suicide, will make way for the health worker willing to help the potential suicide to succeed in his or her endeavour, as our prototype of an altruistic citizen. No matter what the moral basis for such interventions is, their legal impact on the guidelines for social behaviour is obvious.

Therefore, we would have to consider carefully what type of society we are living in. Do we live in a society characterised by solidarity with and acceptance of others, or rather in a society marked by a possessive individualism that pushes us to get rid of our fellow human being, as soon as they become burdens? This way we would be more likely to get it right, when it comes to foreseeing the kinds of behaviours that are bound to increase.

This leads us to a new difference that must be added to the previously mentioned tension between minimalist and maximalist tendencies, when we are considering the internal logic of morals and law.

From the moral perspective, on the one hand, each action takes on a particular relevance, of which we try to make sense. The individual case demands that justice be done, whatever the cost. This is why "*consequentialism*" – which transforms the calculation of practical consequences into a principle of action-, has as little moral prestige as the conviction that the end justifies the means.

On the other hand, from the legal point of view, practical results always have to be analysed responsibly. This does not mean subscribing to pragmatism without principles; – on the contrary, principles usually end up determining the real dynamics of rules. It would mean departing from purely testimonial attitudes, in order to consider the practical consequences of the realization of those principles and their effective social cost. This converts law into a useful instrument to encourage responsibility, rather than an instrument for compassion. Faced with certain "moralising" but understandable longings, we should remember something fundamental: the law cannot solve everything. Its minimalism implies a renunciation of the ambition to answer all human problems or satisfy all needs.

For example, it is not difficult to foresee theoretically – and to have our prediction backed up by practice – that the decriminalization of euthanasia would seriously affect the respectful attitude towards life, professed by health workers. At the same time, the patient's confidence in these health workers would undergo an ambivalent deterioration. The transition from a death that is the result of explicit and repeated personal requests, to a death that is the outcome of an alleged request or one expressed by a third party – or the simple elimination of a life on the grounds that its precarious situation has stripped it of all its value – is a sad reality that must guide us in the strictly legal resolution of this polemic.

Multiculturalism, often rooted in dissenting religious convictions, must come together in this internal logic of legal reality. The same Europe that overcame religious conflicts, thanks to a shared "*ius gentium*", will need to resort to this right once again, in order to bridge intra-national cultural divides.

5. A Renunciation of Life, or the Right to Die? The existence of un-renounceable rights reminds us that the foundations of law go beyond pure individual will.

We are not entitled to everything we want. We do not even have the right to satisfy all our moral aspirations, if they cannot be reconciled with the equally legitimate claims of others. Indeed, in certain circumstances the law – far from being the blind instrument of individual will – even protects individuals from their own shortcomings, giving rise to a controversial "*paternalism*".

The right to education is a perfect example. In Spain, schooling is mandatory up to 16 years of age. This is a right that cannot be renounced, not by the alleged beneficiary in his longing for more enjoyable pastimes, or by his short-sighted compliant parents. Likewise, it would not be acceptable for someone to renounce their own freedom and sell themselves into slavery. The retired professor of Roman law, protagonist of the Spanish film "Stico , who wanted to sell himself as a slave, is a case in point (1984).

Could the right to life be considered un-renounceable as well? Many people would defend this statement, for they believe that life is the most valuable legal good, which conditions the possibilities of exercising any other right. There is also ample scope for "paternalist" arguments, which emphasise that many people who wanted to die, or even tried to commit suicide, were eternally grateful to those who prevented them from doing so.

However, the presence of incurable and irreversible pain represents an exceptional situation. Arguments of solidarity, which are especially effective when questioning individual judgments, lose their strength of conviction in these cases. The argument that we need to live for the sake of others, regardless of our suffering, no longer holds up when we have become burdens and the pain we inflict on others is as oppressive as the physical pain we are feeling, or even more so.

If we take religious arguments into account, the panorama changes radically. If we accept that God is the only Lord of both life and death, that pain falls under his providence as well and may even have beneficial effects, it is easier to argue that nobody has the right to take their own life. Life thus becomes morally "compulsory" and irrenouncable. Would it be the same in the legal sphere?

The situation is paradoxical. If the terminal patient agreed with these religious arguments, they would determine his attitude and thus, the problem would not arise. However, if the patient does not hold these convictions, it does not seem logical, within a pluralist and secularized society, to force him or her to adopt them by law. Non-confessional moral reasons do not provide a foundation that justifies a clear legal response.

However, the acceptance of the existence of a "right to die" is a very different matter. The range of qualifications that can describe our conduct goes beyond the dilemma of "crime or right". There is some criminal behavior that is forbidden and punished by law. However, even if it were no longer classified as criminal, this would not automatically convert it into rights. Even though we are free to do all that is not forbidden, this does not mean that we should flout this mere possibility and hold it up as a right.

Thus, we do not have the right to do everything that is not prohibited. We can simply do it, without necessarily receiving a reply in the form of legislation. Behaviours that are generally seen as permitted or tolerated – as they are not criminalised – only become rights when the person carrying out this behaviour has a legitimate title to it that enables him or her to seek legal protection. That is why the Spanish Constitutional Court claims that for a mere possibility to be converted to a legal demand, it is necessary to analyse the objective of that particular exercise of freedom (STC 137/1990, F.5; STC 11/1991, F.2).

Although it is true – at least in theory – that the decriminalization of certain behaviours, or the recognition that they do not call for criminal sanctions in certain cases, does not convert crimes into rights, experience has shown us that – in practice – this can nevertheless happen. This is another graphic example of the pedagogical and promotional function of rules that we mentioned before.

From a legal point of view, a legitimate title to demand that another human being put an end to our life – or to demand that they eliminate the life of another who is determining ours – would paradoxically entail a degree of "solidarity", which exceeds the minimalism of the law. The decriminalization of euthanasia – as has already happened with abortion – would lead to a demand for legally determined conduct, instead of a mere appeal to moral altruism. This has been illustrated by the experience of doctors in the public health system who were obliged to allege *conscientious objection* if they did not want to participate in abortions that, as they did not constitute a right, did not imply a duty either.

6. A Good Death, Rather Than A Bad Life It is obvious that we will have great difficulty finding moral arguments against euthanasia when it is clearly and repeatedly requested by the patient, unless we subscribe to some transcendental point of view, capable of playing down our capacity for self-determination of our own lives. Arguments of solidarity cannot help us much either. They are problematic in circumstances that are so painful, that regarding our own life as a burden to others could be seen as a manifestation of "solidarity", while the wish to free them from this burden could be deemed "altruistic".

Even if we do not recognise that terminal patients have a right to die, their moral choice to do so may be legitimate. The alleged solidarity of the person who facilitates this death could be considered legitimate as well, although not in the same degree. If we want to express our solidarity with patients, we would do better trying to help them make some sense out of their situation. These moral arguments might be sufficient to back up decriminalization, but only in the absence of strictly legal reasons like the ones described earlier.

These strictly legal arguments are even stronger when pitted against the moral approach that, though rejecting the idea of a right that can be renounced, nevertheless bases its recognition of life as a right on the existence of some minimum levels of quality of life. This introduces a new and particularly disturbing element in the debate.

The subjective free self-determination of the terminal patient now makes way for the evaluation of certain, supposedly objective, conditions by a third party. These conditions alone can then justify the elimination of a life that is no longer seen as a right. We should rule out the possibility that the will to survive might be enough for such conditions to be met. That would be equivalent to admitting that life has the quality that each person subjectively decides to confer upon it. This in turn would imply a defence of the renouncable character of the right to life, a position that we had rejected up until now.

Once again, we have come across legal arguments, as opposed to moral arguments, that make the decriminalization of euthanasia inadvisable. Nevertheless, the social consequences of such a decision should not be ignored either: high treatment costs for terminal patients, the pressure on public hospitals for more beds, the need for organs for possible transplants, and the personal and economic deterioration of the patient's family life….

7. Rights Against the Majority Recently, the ill-considered topic that automatically links democracy with axiological relativism has gained ground. The will of the majority represents the only valid public policy criteria. However, the Rule of Law is based upon completely different foundations.

So far, in Spanish legislation, there has been no constitutional pronouncement on the decriminalization of euthanasia, or on cooperation in suicide, as it is euphemistically referred to in the Penal Code. However, there are some criteria that may be used as a reference point. There are some societal goods (such as the life of an unborn baby) that the state must defend, even though there is no one to claim that particular right. Furthermore, the state must protect any life, even against the will of the person who holds the right to that life, as is the case for example of prisoners commended to the charge of the penitentiary authorities who are engaged in a hunger strike (*Spanish Constitutional Court*. STC 120/1990, F.7).

The state cannot be neutral when it comes to the protection of public goods, and its defence must be especially rigorous when dealing with the demands of the majority. Historically, the fight for human rights has always been based on utopia, rather than clichés. Legally, this fight has been translated to the protection of minorities, through formulas that enable us to control the constitutionality of those laws that reflect the majority consensus.

It is also relevant that when it comes to the regulation of fundamental rights, popular legislative initiatives, which according to the Spanish Constitution require the support of half a million voters, are excluded.

The conflict between opposing positions, founded on religious or moral convictions related to the predominant culture, can hardly be resolved by declarations of peace. The exclusion of religion, and its cultural expressions, from the public sphere, does not necessarily liberate social coexistence from all tensions. The idea that the level of state inhibition with respect to a particular problem, must be proportional to the level of public tension it generates, is surely paradoxical.

This level of political concern, raised by a particular social debate, should instead be treated as a symptom of the need for state intervention, given its relevance to citizens. When legal restraint is chosen under these circumstances, some latent moral prejudice must have influenced that choice.

Behind the expression of the "neutrality" of the public power, there lies an unspoken faith in the pre-established harmony of individual morals. The conviction that each person can organise his or her own life as it suits them seems harmless enough, as long as no third party attempts to claim our solidarity. In this respect, the possessive individualism that plays an important part in the polemic surrounding abortion – claiming the right to the ownership of one's own body – is an eloquent example.

However, in a multicultural context, secular prejudices can sneak in as well. According to these, the controversy is not unclenched by the importance of the goods involved, but by fanaticism, introduced into the neutral public sphere by religious fundamentalists. Furthermore, a person can be accused of fundamentalism, simply because he or she dares to defend certain principles. Therefore, neutrality demands that we opt for more imaginative and relaxed alternatives.

However, fundamentalism can really take over when arguments and debates are abandoned in favour of violence. This can also happen when any distinction between moral and social demands is rejected, as it is understood – in the fundamentalist way – that the law should deal with both.

Trying to exclude from the public sphere all that is associated with fundamental beliefs, or all issues whose defence could generate controversy, would lead to the imposition of a trivial kind of monoculturalism, without any debate. This would lead to a devaluation of democratic debate, which would be relegated to the discussion of largely unfounded proposals, formulated without conviction and deemed unworthy of serious consideration.

We can hardly expect to reach a multicultural dimension if we let previously insurmountable difficulties stop us from accepting certain meaningful aspects from the cultural sphere. This is particularly so when these are aspects that could facilitate cross-cultural understanding.

Going back to the relationship between democracy – so representative of our culture – and relativism, we are confronted with a paradox. The negation of certain objective foundations underlying humanity converts cultures into mere accidental outcomes that are mutually incompatible. If we are not allowed to consider anything as more true or false, more legitimate or illegitimate than its contrary, we can only proceed to the imposition of a hegemonic culture, embellished by the few exotic cultural features it is capable of assimilating. Only if we view cultures as historical and plural expressions of a common human nature will we be able to find the necessary basis for such a multicultural dimension.

The existence of legal demands based on objective principles becomes a requisite for the creation of compulsory rules that go beyond the mere imposition of a kind of cultural colonialism by a culture that, backed by relativism, proclaims itself unquestionable.

Only if we are guided by objective elements, when tracing the line where moral and legal demands overlap, can we put a stop to fundamentalist attempts at subjecting public life to an all-encompassing religious code. Paradoxically, the current negation of natural law works in favour of such fundamentalist beliefs.

Only if we base ourselves on objective principles when deciding which culturally alien elements to include in an ethical minimum to be enforced by law, will we be able to avoid the exclusion which may underlie multicultural coexistence.

RELIGIOUS BELIEFS WITHIN A PLURAL SOCIETY

As its title announced, this analysis would not be complete without further reference to the issue of religion in a pluralist society.

We touched upon religion when we saw how a moral response to the question of euthanasia would be much easier if we recognised the supremacy of God over all human life. However, it would be virtually impossible, departing only from moral beliefs, to legally impose this solution upon a society where believers, unbelievers and people radically opposed to religion all coexist.

However, religion has not lost its relevance. My experience has convinced me that a solution that does not respect its creed would stray from the path of truth. Although this has not given me the authority to transform this conviction into an argument capable of finding a legal solution for this problem, it has encouraged me to keep on looking for other arguments that would convince my fellow-citizens that the decriminalization of euthanasia ought to be rejected.

On the one hand, spreading this conviction among my fellow-citizens through the methods available in a pluralist democracy would help to achieve the necessary consensus on this issue. On the other hand, it might be the most effective formula to transform those behaviours that push the sick to consider themselves a burden and stop us from making any sense out of pain by or simply suggesting that putting an end to human life might be the most effective way of preventing pain from ruining our social environment.

REFERENCES

Marx, K. (1970) Zur Judenfrage. Marx-Engels Werke. Dietz, Berlin.
Stico (1984) Directed by Jaime de Armiñán. Main actor: Fernando Fernán Gómez.

PART IV

FUTURE LEGAL ORDERING AND SOCIAL PLANNING

CARLOS M. ROMEO-CASABONA

CHAPTER 16
INTERNATIONAL LAW AND GENETIC COUNSELLING

CONCEPT AND RELEVANT ASPECTS

From a legal point of view genetic counselling raises a variety of interesting issues, not only because of its role – in a strict sense – of providing and evaluating genetic information, but also due to the tests that are performed and the possible decisions patients can make with this information. Genetic counselling can be defined as "the process whereby patients or their next-of-kin who present a risk of hereditary disease are advised as to the consequences of the disease, the likelihood that they might suffer it or pass it on, and the possible methods to avert or in some way mitigate these consequences" (Harper 1990, 273).

Genetic counselling is composed of a number of phases, all of which raise a variety of different ethical and legal concerns: (1) advice on the appropriateness of submitting oneself to certain diagnostic tests and the decision whether or not to undertake them; (2) actual performance of the tests, which will differ depending upon the time at which they are conducted and the aims pursued in light of the results; (3) communication and evaluation (advice in the strict sense of the term) of test results; and (4) decisions made in light of the information. From a different perspective, it is also necessary to draw a distinction between, on the one hand, the responsibilities that lie with the experts who give advice at the different stages and the specialists who perform the diagnostic tasks; and, on the other hand, the responsibilities that lie with those who make the decisions on the basis of the supplied information, in the majority of cases this will be the persons seeking counselling (Romeo-Casabona 2002, 92).

From a legal standpoint, one first has to examine the criteria afforded by current domestic laws and international statements regarding the lawfulness of the different actions and the measures that can be taken with respect to genetic counselling. In addition, it is also important to examine how these laws deal with responsibility for wrongful actions. Thus, we will examine these matters in light of various national laws (e.g. Spain, France, Norway, China, and India), as well as various international documents (e.g. the World Health Organization (WHO) Report concerning "Proposed International Guidelines on Ethical Issues in Medical Genetics Services" (1988), Council of Europe (*Convention on Human Rights and Biomedicine* (1997), and *Recommendation* on "Prenatal Genetic Screening, Prenatal Genetic Diagnosis and Associated Genetic Counselling" (1990)) and UNESCO (*Universal Declaration on Human Genome and Human Rights* (1997), and *Universal Declaration on Human Genetic Data* (2003)), among others.

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 217–233.

GENERAL FRAMEWORK

Consultation normally begins in the context of reproduction-related decisions. Antenatal diagnosis is the range of associated diagnoses that are given importance either prior to the decision of having children – preconception and pre-implantation diagnosis – or during the course of the pregnancy, as is the case with prenatal diagnosis. Hence, persons who seek this counselling tend to be couples (married or otherwise), although only one person may be involved (particularly in preconception diagnosis, but also in pre-implantation if the transfer of embryos to a single woman without a male partner is permitted). Postnatal diagnosis relates more directly to the possibilities of treating or preventing hereditary illnesses in newborn babies, children, and even adults. By first determining the family history regarding the transmission and/or appearance of genetic abnormalities, and then by investigating the couple themselves, the necessary data for each for each of these diagnoses is obtained. Genetic analysis (in the oocyte or in the *in vitro* embryo) through a variety of different tests in which other qualified specialists, particularly gene biologists, participate alongside the doctor, is commonly used to investigate couples.

At this point it is important to remember that all international documents on human genetics proclaim as one of their main principles a ban on the discrimination of human beings based upon his or her genetic characteristics (i.e. the *European Convention on Human Rights and Biomedicine*, art. 11; UNESCO'S *Declaration on Human Genome and Human Rights*, art. 6).

Competent Professionals to Provide Counselling When different professionals are participating, an area that still remains unclear is which professional should provide the counselling (Emaldi 2001, 89). One can assume that this is the job of the physician, and what is important is not so much their specialty, but that they are actually specialists (i.e. clinical geneticists); but also that genetic counselling as such can be provided by geneticists. They must have the knowledge and practical experience to enable them to counsel – a role that has normally been carried out by gynaecologists and paediatricians. Specialists (gene biologists) should conduct genetic tests in approved centres. In this respect, the Council of Europe Recommendations stipulate that prenatal screening and diagnosis must be undertaken under the responsibility of a physician, and that laboratory tests be carried out in centres that have been approved by the state or the competent authority. Furthermore, according to the WHO guidelines, all services, including laboratory procedures, should be submitted to ongoing quality controls (Wertz et al.1995). Performing Genetic Tests: The Need for Genetic Counselling The European Convention on Human Rights and Biomedicine reflects the concern that these types of tests be provided only under appropriate genetic counselling: "Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling" (Art. 12). In a similar way, the WHO *guidelines* recommend that "genetic screening and testing should be preceded by adequate information about the purpose and the possible outcomes of the screen or test and potential choices to be made," as well as that "test results should be followed by genetic counselling, particularly when they are unfavourable" (Table 4 of the Guidelines).

The Offer of Genetic Testing Except where persons seeking advice directly approach a physician specifically for this purpose, in the majority of cases a physician will be dealing with his own patients. In the latter case, physicians should consider the possibility of offering genetic counselling of his own initiative, particularly if he is aware of a previous family history or that a previous child has had problems of a hereditary nature. Offering the appropriate diagnostic tests will depend on the existence of adequate diagnostic procedures for each specific situation (i.e. the existence of a pregnancy, the stage thereof, age of the expectant mother, whether assisted reproduction procedures are being used, etc.) and for the hereditary transmissible disease under consideration. In this regard, the Council of Europe *Recommendations* indicate that diagnostic tests should not be undertaken if prior or subsequent counselling is not available and when they are performed they should be done so with the sole purpose of detecting serious risk to the child's health. In the same vein, UNESCO's *Universal Declaration on the Human Genome and Human Rights* proclaims that research, treatment, or diagnosis affecting an individual's genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of national law (Art. 5, a).

According to the WHO guidelines, physicians should refrain from providing tests for procedures that are not medically necessary. The consulted physician should be familiar with the available procedures and the centres or laboratories where the diagnosis can be carried out. Moreover, they should be sufficiently qualified to evaluate the results and other information obtained from the patient's medical history. A physician who is aware of a prior medical history and does not offer such tests, or if he refuses to provide them once they have been requested (provided that the persons seeking them can provide sufficient evidence of a serious health risk to warrant them), may be legally held liable.

Voluntary or Compulsory Performance of Tests Testing and diagnosis will be only performed subject to the previous free and informed consent of the patient. Compulsory testing of the population in general (genetic screening) or of the identification of population groups at risk should be ruled out for several reasons (Fletcher 1980, 130). In purely financial terms, it is extremely expensive, bearing in mind the low incidence of genetic abnormalities in the overall population. This despite the fact that a growing number of abnormalities, both prior to conception (pre-conception analysis) and during pregnancy (prenatal diagnosis) are being identified and classified by experts. However, this argument has not deterred some authors from advocating for the implementation, in the United States in the near future, of mass compulsory diagnoses (so-called neonatal diagnosis) for children in order to detect treatable genetic diseases (Shaw 1984, 575).

In my view, genetic screening or neonatal diagnosis of newborn infants may be an appropriate public health measure, and should even be made mandatory in the case of certain serious and well-known illnesses. However, this should be undertaken only if it marks the starting point of a program designed to treat or voluntarily prevent the disorders, does not lead to discrimination of any kind against the parents or child, and as long as the duty of confidentiality is observed. A similar approach is adopted in the WHO guidelines which endorse mandatory and free screening when early diagnosis and subsequent treatment will be beneficial to the newborn.

From a legal point of view, public health requirements that are geared toward safeguarding the "quality" of the human species – e.g. the prevention of the risk of a "defective" population – cannot be justified in light of the significant intrusion into privacy, personal and family liberty such investigations entail. The powers granted to national authorities to provide for and protect public health through preventive measures and the establishment of medical services and facilities is limited by a respect for human rights and dignity.

The previously mentioned guidelines would scarcely be compatible with the practice in some countries to insist on a "pre-matrimony" diagnosis of couples. A possible exception to this would be the case where test results are communicated only to the person tested – not to his/her partner – so that he/she can then make the appropriate decision. However, one should also consider that, even here, implicit pressure would be brought to bear upon the person and, hence, such an exceptional situation would perhaps not be appropriate given that the partner would inevitably be concerned or even suspicious of not being told the results of the test.

The Council of Europe *Recommendations* states that making diagnosis routinely available in no way excludes the requirement of informed consent (Principle 7). More comprehensively, UNESCO‘s *Declaration* stipulates that in all cases, a person's free and informed consent shall be previously obtained (Art. 5, b). However, examples of the opposite also exist: in Cyprus, genetic screening for thalassemy is mandatory for all persons wishing to marry (Hadjiminas 1994, 27). There, couples must certify that they have undergone the corresponding tests and are aware of the results. A pre-marital certificate is then issued, which is then accepted by the Cypriot Church. In the People's Republic of China, prior to marrying, all couples must obtain a certificate that shows tests have been performed for the following three groups of disease:[1] (a) serious genetic disorders, (b) infectious diseases, and (c) serious mental illnesses. However, in this case mere presentation of the certificates to the authorities is not in itself sufficient: couples should take some precautions before marriage will be allowed, as we shall see below.

Directive or Non Directive Genetic Counselling It must also be considered whether genetic counselling; the performance of diagnostic tests, and decisions taken in light of such test results should be voluntary or obligatory. Put in another way, could the competent national health authorities legally impose a particular decision or measure upon a person, group of people, or on the population as a whole? Clearly, this is a health policy issue that stretches far beyond the initiatives of genetic counsellors and – given that an element of coercion is involved – such a state of affairs would affect the fundamental rights of individuals and, indeed, the very constitutional framework in democratic countries.

The European Council‘s position on this matter is clear in that it opposes mandatory counselling: “The counselling must be nondirective; the counsellor should under no condition try to impose his or her convictions on the persons being counselled but inform and advise them on pertinent facts and choices” (Principle 4). The WHO guidelines also consider a non-directive approach, except when treatment is available.

Confidentiality in the Use of Information Obtained Lastly, it is worth noting some of the conflicting situations that may arise as a result of antenatal diagnosis. In many cases physicians find themselves in an awkward position when the diagnosis confirms that the person or persons seeking counselling carry pathological genes that might transmit hereditary disorders to their offspring. Should physicians personally disclose this risk to the family members, or trust that the persons seeking counselling will do so and thus enable family members to seek appropriate advice or preventive measures? Keep in mind that the family members most at risk are children, given that the deleterious gene may have yet not manifested itself and, hence, the disease may still be in the larva stage, or the person's predisposition may not yet be obvious. Knowledge of the situation is crucial in order to allow these persons to receive adequate treatment. A duty of confidentiality, however, only disappears in those cases expressly stated by the law or when a judge determines that there are higher legal interests to protect. In all other circumstances, a doctor cannot breach his duty of confidentiality without his patient’s previous consent. This duty also extends to an individual’s genetic information. It is up to the individual to decide as to whom, how, and to what extent such information should be disclosed. Thus, divulging information obtained through genome analysis is prohibited unless the person concerned or his or her legal representatives consent to it. This prohibition applies even to situations where a conflict of interest exists because the party requesting the information is an affected person’s family member and is demanding the information in order to determine whether he has inherited a pathological gene similar to that discovered in the patient.

Just as a patient has a right to information or right to know, it is now commonly mentioned that a person also has a right “not to know” (Rodotà 1992, 24; Nys et al. 2002, 95). In other words, a person has the right not to come forward for genetic tests in order to avoid knowing whether or not he is carrying a genetic disease. This attitude might be considered selfish if it blocks scientific progress or if it prevents family members or future offspring from learning of the condition and, thus, it might be tempting to institute mandatory testing for these people. However, it should be noted that anyone who tries to invoke the so-called “right not to know” (a “right” of which he or she may probably be unaware) starts from the position that he or she “already knows.” The manifest wish not to undergo testing implies that the individual already knows that he or she belongs to a genetic disease risk group or at least is aware of a similar previous family history. He or she may even know that science does not have adequate means to prevent, treat, diminish or mitigate the genetic disease. That is why the individual chooses not to know whether he or she is carrying a deleterious gene or is going to suffer from a disease, particularly if this disease is serious or deadly. So that this information may not alter his development and social advancement from that moment onward, the individual chooses not to know something which neither he nor science, can do anything about. Consequently, the right to protection of one's privacy serves to recognize an individual's decision in this respect. In this way, the right not to know is really just a manifestation of the right to have one's private and family life respected. As it is known, the right to respect for private and family life is expressly recognized in the 1950 European *Convention for the Protection of Human Rights and Fundamental Freedoms* (art. 8.1).[2] According to this Convention, this right can only be limited "in accordance with the law and is necessary in a democratic society for the protection of health and morals, or for the protection of the rights and freedoms of others" (art. 8.2). For its part, the *European Convention on Human Rights and Biomedicine* also underscores the importance of the right to privacy in the field of biomedical sciences (art. 10.2), [3] and recognizes similar restrictions as those found in the previously mentioned *Convention*. In this respect, Article 26.1 of the *European Convention on Human Rights and Biomedicine states*:

> The nature of *European Convention on Human Rights and Biomedicine* provisions cited just now, as regards possible restrictions, which could well be relevant for the purposes of our considerations here, is qualified nonetheless by the proviso "no restrictions shall be placed on the exercise of the rights and protective provisions contained in this *Convention* other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others" just as certain intrusions in the private life of individuals may be admissible in order to prevent the risks of a contagious disease.

Respect for confidentiality is also mentioned by the WHO guidelines, and more specifically the protection of the privacy of individuals and families from unjustified intrusions by employers, insurers, and schools.

GENETIC TESTING AND DIAGNOSIS

As was mentioned above, the performance of the appropriate tests for each type of diagnosis considered below must conform to the general requirements of informed consent (Emaldi 2001, 165). More specifically, the consulting doctor must provide all information with great detail and care. This obligation, however, is magnified with respect to information concerning test objectives, the risks they entail for the expectant mother and the foetus, and the margin of error of the results (Harichaux 1992, 442; Romeo-Casabona 2002, 101). Given the characteristics of preconception and prenatal diagnosis, informed consent would apply also even to minors with a natural capacity for judgment (e.g. a pregnant girl), and neither the physician's or a parent's criteria should be imposed on them.[4]

Preconception Diagnosis Pre-conception diagnosis refers to the information given by a physician or a geneticist counsellor to a couple, married or otherwise, or to *an individual prior to pregnancy. The information concerns the risks of giving birth to a child with a disease or malformation of a genetic or hereditary origin.* This type of testing is generally sought where one of the family's children has been born with malformations of a genetic origin. Of late, more and more people are seeking "predictive" diagnosis based upon risk factors derived particularly from known family histories. They do not necessarily wait for the birth of an affected child. As part of public health policy, preconception diagnosis can be used to investigate population groups, especially where one or some of the groups present a high risk of transmission or risk that they will suffer genetic abnormalities. This is what is known as genetic screening and can be carried out on all members of the population.

Three problems arise in connection with the use of such tests (Walters 1982, 486): (1) the weighing of potential risks and benefits; (2) the use of scarce resources for such tests; (3) the voluntary or compulsory nature of the tests. As it was dealt with only briefly and due to its relevance in terms of an individual's fundamental rights, [5] we will dwell on the last of the three issues, particularly as it relates to preconception genetic tests.

Compulsory screening of high-risk couples leads us a different type of consideration (Romeo-Casabona 1994, 197, 378). Compulsory diagnostic testing of such groups (or to be more specific, prenatal diagnosis with pregnant women) could serve two goals. Firstly, it might help make a couple aware of the probability or degree of seriousness of the disease – or the risk of passing on hereditary diseases or abnormalities to their offspring. In this way, the couple could make the responsible decision of having children or, conversely, as we will see below, they might opt to take steps to prevent it. Secondly, it might allow the State, according to a couple's decisions and considering the results, either to take appropriate measures to prevent or restrict reproduction by the couple or through health measures to prevent the risks or to reduce the effects of its occurrence. In each case, the State should provide the affected couple with the necessary means and services in order to eliminate or alleviate the burden that such a child would represent to them. Even with these arguments, however, one would have to favour voluntary (as opposed to compulsory) testing for the same legal reasons mentioned above, and to ensure that women are not discriminated against in terms of assistance, depending on their decision to agree or refuse to undergo testing.[6]

The aforementioned situation belongs to the private sphere (family privacy), in that it concerns a couple's decision to want a child despite the formidable risk that he or she may be born with a serious physical or mental handicap or, conversely, not to have a child, provided that the mandatory legal requirements are fulfilled. The second situation has far greater social connotations, and raises the question of whether there is an absolute individual right to procreation or whether certain restrictions or even the negation of said right would be admissible in extreme cases.

Pre-implantation Diagnosis Pre-nidation or pre-implantation diagnosis is carried out in embryos obtained in vitro prior to their transfer to the woman. It is also accompanied by genetic counselling for the future parents. Extreme precautions *are always taken in view of the complexity involved (high risk of morbidity and lethality), the limited number of applications at present, and the gaps in knowledge that currently exist regarding its effects (Lenoir 1991, 57). Some domestic laws are currently not opposed to obtaining a single cell from a zygote and performing tests on the former in order to determine whether or not to implant the zygote (Romeo-Casabona 2002, 95). This does not mean, however, that doubts do not exist regarding the appropriateness of this technique given the tremendous eugenics potential involved. Bear in mind that this technique permits the intervention of several embryos and could be used not only to reject an embryo or embryos (for transfer to the woman) due to the presence of a pathology, but also, on the contrary, to select the most suitable embryo from a health standpoint or for other non-pathological interests.*[7] In fact, under Spain's current *Law on Assisted Reproduction Techniques*, which dates back to 1988,[8] pre-implantation diagnosis is allowed only under very strict conditions. Similar legislation was introduced in France in 1994,[9] and Norway in 1995, among other countries (Emaldi 2001, 114).[10]

Prenatal Diagnosis Discoveries being made in human genetics currently make it possible to determine and analyze the foetal genetic component, and it is partly do these discoveries that the doors to the use of various therapeutic measures on foetuses has been opened. Prenatal diagnosis, however, has also played a role in introducing an element of prediction in medical practices (Romeo-Casabona 2002, 97). Prenatal diagnosis is understood as the range of medical procedures available to obtain information on a foetus' congenital defects. To be more precise, this form of diagnosis refers to "all prenatal actions designed to diagnose a congenital defect – i.e. all abnormalities in morphological, structural, functional or molecular development that are present at birth (although these may manifest themselves at some later date), whether they be external or internal, familiar or sporadic, hereditary or otherwise, single or multiple" (Carrera 1987, 5). This diagnostic procedure can be used to detect the presence of a disease or malformation in the foetus and even predict its sex, which can also be useful to highlight gender-related hereditary diseases. In the case of couples presenting a high risk of having offspring with abnormalities (this would include relatively elderly expectant mothers), it serves to confirm or rule out the presence of abnormalities in the foetus. Although the foetus is the subject of prenatal diagnosis, the information may also benefit its parents since it allows them to know whether or not one of them is carrying a destructive gene that may have been passed on to the foetus. When it is diagnosed that the foetus is at risk of suffering of a certain disease at some point in the future, prenatal diagnosis leads to genetic counselling, which allows certain decisions to be taken in time and problems to be treated early.

Medicine has at its disposal a variety of techniques available for the early detection of a range of foetal abnormalities: ultrasound, foetoscopy, x-rays, amniocentesis, funiculocentesis or direct access to foetal blood, choriocentesis, taking blood from the mother, etc. (Fraser 1980, Carrera 1987, 161; 3; De la Fuente

1992, 13). Amniocentesis, whether done early or later on in the pregnancy, currently permits diagnosis of a greater number of congenital diseases due to chromosome deviations, metabolic imbalances of the neural tube, non-hereditary genetic diseases linked to sex, and predisposition (predictive diagnosis) to diseases that will appear during childhood or adulthood, etc. (Carrera 1987, 8).

When invasive, the techniques do pose certain risks for both the foetus and the mother. Negative consequences include loss of the foetus (spontaneous abortion, womb death, and stillbirth), foetal lesions and infections, neonatal disturbances, and complications for the mother (visceral perforation, premature detachment of placenta, early breaking of waters, infection, syncope and death, contractions and premature delivery, postpartum bleeding). Hence, insistence is required that these techniques not be offered indiscriminately and be used only when absolutely necessary. Merely trying to avoid risks is not a sufficient reason to use these techniques (Harichaux 1992, 440). Nevertheless, these techniques are constantly being perfected and their inherent risks being reduced. The risk of postamniocentesis is below 2%, as is the overall figure of risks to the mother (Knight and Mann 1983, 155; Esring and Leonardi 1985, 321).

In view of the array of diagnostic possibilities currently offered and those that will be shortly available through prenatal diagnosis, it might be appropriate to indicate the major aims they serve: (a) to allay the fears of parents with high risk histories that the foetus is free from malformation or disease; (b) to permit foetal therapy (genetic, surgical, or drug-based) to cure or palliate certain abnormalities; (c) to indicate the means of delivery, depending upon the malformations present in the foetus (e.g. by caesarean section); (d) to determine the treatment the newborn baby must follow after delivery or at a later stage (predictive-preventive medicine); (e) to decide in favour of embryopathic abortion, where lawful; (f) to decide in favour of abortion as a means of gender selection, where permissible by law; (g) to accept that the child is likely to be born with abnormalities or to begin the legal steps for adoption or for admission into a children's home (Powledge and Fletcher 1980, 92). The decision in each case will depend upon the parent's personal convictions and the possibilities offered by a country's legal system (i.e. the option of abortion). It has already been noted that the wide range of possibilities offered by prenatal diagnosis – which after all permits better gynaecological and neonatal care – does not necessarily lead to an indiscriminate rise in the number of abortions, thanks to recent advances in perinatology (Carrera 1987, 8).

Thus, from a foetus' perspective, prenatal diagnosis presents some ambivalent features that can be used to benefit its own vital development during pregnancy or after birth. It can help in deciding in favour of abortion when the diagnosis confirms suspicions of malformations – as required by the law for abortion to be authorized – or it can help the mother in her decision (in accordance with the maximum time-limits systems) (Guenther 1987, 226).

Consequently, in legal terms, there is no reason not to view prenatal diagnosis as a therapeutic measure, just like other diagnostic procedures, as long as it aims to treat the foetus to the extent that is currently possible (Eser 1985, 351; Montano 1991, 75). For this reason, it should be not considered a criminal law offence, as would, for example, an assault causing bodily harm. With prenatal diagnosis, contact with the mother's body or the embryo is done in their best interest and with the goal of obtaining a diagnosis; none of these elements are present in a bodily assault. In addition, a prenatal diagnosis cannot be considered an assault when in the diagnosis there is a clear indication of the risks and benefits involved. Moreover, all actions must conform to the *lex artis* and the mother's informed consent must have been obtained. Diagnostic techniques that involve a certain experimental component (therapeutic experimentation) and an element of risk (amniocentesis) can also be included in this category (Eser 1985, 351; Guenther 1987, 230). If diagnosis is performed with a possible abortion in mind, given the slight nature of the injuries that could certainly be caused during the diagnostic tests (equivalent to very minor bodily harm), the actions would be covered by the pregnant woman's consent, since she is the one who sustains the injuries in the first place.

The lawfulness of prenatal diagnosis in Spain is further confirmed by Law 35/1988 on *Techniques of Assisted Reproduction*. According to this law, "all interventions on living *in vitro* embryos or on foetuses, inside or outside the uterus, for diagnostic purposes are unlawful except if they aim to achieve the well-being of the *nasciturus* and to favour its development or if they are supported by the law" (art. 12.2). Express authorization is given even for the use of gene technology for prenatal diagnosis.[11] As a consequence; diagnosis is permissible strictly when it is used as an instrument for the benefit of the foetus. It should be interpreted that this excludes diagnosis carried out for the purpose of investigation, experimentation, or for other non-therapeutic purposes.

The *First Final Provision* (letter d) of the aforementioned law requires the government to compile a list of genetic or hereditary diseases detectable through prenatal diagnosis. This list has still not been approved and, thus, one wonders whether unlike foetal therapy, such tests are not permissible until this list is compiled. In this regard, further delay in publishing this list could have very negative effects in the near future. However, non-compliance with this requirement does not give rise to an administrative offence or sanction. In any case, one should not forget that the approval of such a list could also have important consequences for abortion performed for embryopatic reasons. This is likely considering that the list will probably limit prenatal diagnosis to cases in which very serious diseases are present. The existence of such a disease would in turn provide possible grounds for an abortion (depending also upon the specific characteristics of seriousness, likelihood, etc., present in each case).

Similar to preconception diagnosis and genetic screening, there has also been discussion on whether prenatal diagnosis should be voluntary or compulsory. For the same reasons outlined above, the best solution is to leave the decision up to the responsibility and free choice of the couple or expectant woman. However, this decision should not be made subject to the proviso that abortion must necessarily follow if pathologies are detected in the foetus (International Association on Penal Law 1988, 285; Harichaux 1992, 445). Neither should it lead to discrimination in terms of access to the assistance or social services that come with pregnancy and motherhood. It must be acknowledged, however, that prenatal diagnosis does pose problems of a different kind.[12] In this regard, the Spanish Law on *Techniques of Assisted Reproduction* requires that the couple or, where appropriate, the single woman must be thoroughly informed of the procedures, diagnostic investigations, possibilities and risks of the proposed therapy, and must accept them beforehand (art. 13.3). It should be noted that the law requires consent not just for therapeutic actions, but for all procedures. This is a conclusive argument in favour of the view that all such tests should be voluntary. For similar reasons, we should rule out the use of invasive procedures as a form of indiscriminate genetic screening, which should be used only when indicated (e.g. if a parent or family member has a history of risk or when previous children of the couple have suffered disorders or if risk situations have occurred during pregnancy (infectious diseases in the mother, exposure to radiation, etc.).[13]

Chinese law, however, favours a directive approach that in certain cases even covers prenatal diagnosis. A doctor may authorize prenatal diagnosis if foetal abnormality is detected or suspected after an examination (art. 17). It is the doctor's responsibility to explain to the couple and to advise them with respect to termination if the foetus is suffering from a serious genetic disease, carrying a serious malformation, or if, as a result of a serious illness in the mother, continuation of the pregnancy might place her life in danger or seriously endanger her health (art. 18). *Apparently*, the couple should be able to freely decide whether to terminate the pregnancy or to undergo sterilization.[14] The law renders compulsory medical counselling and guidance in the case of couples suspected of suffering a serious genetic disorder or, prior to having a second child, if they already have a first child with a serious malformation.[15] Several questions have arisen in connection with these provisions, among them whether the directive (obligatory) nature of the medical intervention and guidance extends only to the performance of the tests or also to prevention decisions (*apparently* not, as indicated above, which is why we have not included this in the following section on eugenics-based limitations on reproduction). Similarly, questions arise with respect to pregnancies out of wedlock, which would appear to be excluded not just from regulation, but even as a social phenomenon.

In democratic constitutional legal systems, restrictions on the right to reproduce such as those mentioned above appear unlawful especially when this right is exercised in a conscious and responsible manner.[16] The right to found a family, without discrimination of any kind, and the right to the protection of private life are considered a fundamental part of the rights recognized and protected by international declarations or conventions (Romeo-Casabona 1998, 255). This is reflected in the *Universal Declaration of Human Rights* of 1948 (art. 12 and 16), the *International Covenant on Civil and Political Rights* of 1966 (art. 23.2) and the *European Convention for the Protection of Human Rights and Fundamental Freedoms* of 1950 (art. 8 and 12).

Furthermore, the strict family planning policies of some States, designed to contain population growth (which has reached alarming levels in certain parts of the world), have indirectly given rise to dramatic eugenic practices. This is due to the fact that parents are anxious to guarantee that the child they are "entitled" to is born healthy (by getting rid of or abandoning a sick or handicapped child). In other cases, cultural beliefs regarding the preferred sex of the child may also lead to abortion.[17] Examples of legal measures trying to avoid this last scenario are China's *Law for the*

Protection of Maternal and Child Health (art. 32.2 of Law 1994), and India's *Law on prenatal diagnosis* (Law no. 57 of 1994), in which sex determination of the foetus through prenatal diagnosis is prohibited unless it is done to prevent sex-related illnesses. Likewise, the 1997 *European Convention* states that medically assisted procreation techniques shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease are to be avoided (art. 14).

Postnatal Diagnosis From a legal standpoint, this procedure in principle does not indicate any major differences with other diagnostic procedures unrelated to possible genetic diseases. Nevertheless, the fact that it serves to predict predisposition or certainty that a disease will manifest itself, especially when it deals with late-onset diseases, and the question of whether adequate treatment is available or not for the disorder detected, pose a range of complex dilemmas which will not be dealt with in this paper (Nys et al. 2002, 83). For all other intents and purposes, this type of diagnosis comes under the category of actions linked to subsequent treatment or prevention, which in this case would entail additional aspects if somatic line gene therapy were involved. Moreover, with newborns it might lead to euthanasia-related decisions in isolated instances of serious malformation.

COMMUNICATION AND EVALUATION OF INFORMATION

As is generally acknowledged, communicating the information to those persons requesting the advice is a complex matter in genetic counselling in view of, among other things, its highly technical nature (Walters 1982, 489). However, information should be sufficiently clear (to a layperson) and complete so that the person can understand the situation as fully as possible and can make his or her decision accordingly. Lack of data regarding certainty does not mean that calculations of probability may not be included in the information.

In all these cases, information concerning diagnosis results and other tests and examinations on the likelihood of suffering or passing on to offspring a given disease (information concerning gravity, whether the disease is gender-related, possible time of appearance, consequences for reproductive capacity, etc.), and on existing means of prevention or mitigation, are usually – although not necessarily – accompanied by an evaluation or assessment by a specialist. Their job is to confer true meaning to the diagnosis and to help the couple reach a decision.[18] This technical or professional advice should also extend to information regarding what are the possible and available solutions in relation to each specific situation detected. As such, it is lawful that in exceptional circumstances (where the couple does not have sufficient criteria or are unclear as to their situation) and having weighed all of its costs and benefits, the specialist recommend or suggest the most appropriate decision. However, this should not condition the freely-made decision of the couple who must make their choice independently. The physician must not attempt to use such advice as a vehicle impose his own religious, ethical, or moral beliefs.[19] As I have previously explained, coercive or directive advice is not compatible in any way with international rules or recommendations.

Occasionally, there is disagreement as to whether the information should be made available to both persons involved. This creates very unique problems. For example, one person may be against the results being made known to his/her partner. If genetic counselling is given as part of preconception diagnosis (that is, the reproductive capacity of the person (male or female) – whether or not he/she will be able to have a genetically-healthy child), subject to some exceptions that will be dealt with later on, the person's reservations or desire for confidentiality should be respected. The same goes for postnatal diagnosis. However, in pre-implantation or prenatal diagnosis cases, where the male partner is the husband (not separated) and is the biological father or has consented to insemination of his wife, with sperm from a donor, the information should be given to both partners. This despite the fact that legal provisions allow one or the other (the woman in the case of abortion, both partners in the case of consent for implantation of an embryo obtained *in vitro*, etc.) to make subsequent decisions. In this last case, the same interpretation could be made with regards to an unmarried male who has given express consent to donor fertilization of his partner. It is highly doubtful, however, that such a person should be entitled to receive information regarding the prenatal diagnosis of a foetus conceived with a non-marital partner.

DECISIONS MADE ON THE BASIS OF GENETIC COUNSELLING

A range of decisions can be made depending upon test results and the specific situation that has given rise to the consultation. There is only room here to list the possibilities without entering into all the necessary aspects (Romeo-Casabona 1996, 181). We shall assume the common (and extremely problematic) situation that the results show important risks:

1. *Before having children (preconception diagnosis)*:
   a) Prevention of birth:
   - Using contraceptive measures, in accordance with specific statutory provisions.
   - Voluntary sterilization, in conformity each country's legal provisions. Note that, in this last case, consent is required only from the partner who decides to seek sterilization; consent of the other partner is not required.

   b) Having children without risk to offspring:
   - Recourse to appropriate and clinically-available assisted reproduction techniques (e.g. seeking of a gamete or embryo donor), under the terms of the applicable law.
   - Gender selection to prevent transmission of gender-related hereditary diseases.
   - Gene therapy in gametes or in zygote (germ-line therapy). This is forbidden by the *European*

Convention on Human Rights and Biomedicine, if done with the aim to introduce any modification in any of the descendant's genome (art. 13).

From a legal standpoint, there are no objections to using, at the preconception stage, gender selection techniques (using diaphragms or drugs) for non-preventive purposes because these are considered to belong to a couple's private sphere.

2. *Prior to implantation of the in vitro embryo in a woman (pre-implantation diagnosis)*:
    - *a)* Embryo gene therapy, but considering also the prohibitions linked to germ-line interventions;
        - Selection of embryos or the sex of the embryo, for the same reasons mentioned above. However, this is usually not permitted if the aim is not to prevent transmission of hereditary diseases.
    - *b)* Rejection of implantation for procreation, which could be ventured as an alternative to gene therapy on the pre-implanted embryo in a large number of cases, if not all, given that it enables the embryos to be selected.
3. *During pregnancy (prenatal diagnosis)*:
    - *a)* Embriopatic indication abortion, in accordance with domestic provisions.
    - *b)* Foetal therapy (regardless of its genetic or non-genetic nature); this holds great potential for the future, although today the possibilities are rather limited; conflict may arise if the mother, justifiably or otherwise, refuses therapy;
    - *c)* Gender selection on grounds other than the prevention of gender linked diseases: this is not permitted by laws on voluntary pregnancy interruption under the "legal stipulated cases" system, but it would be under the "mother decision along a stipulated period" system.[20]
4. *As a consequence of postnatal diagnosis*:
    - *a)* Therapeutic measures: so-called "euphemic" treatment (dietetic, elimination of metabolic products, administration of product in which the patient is deficient, etc.), or palliative, symptomatic, gene somatic-line treatment, etc. From the legal standpoint, the main issue arising here would be the same as that for any form of therapeutic experimentation, with the corresponding requirements of whether or not alternatives must be available, the weighing of risks and advantages, informed consent, etc.;
    - *b)* Neonatal euthanasia: this is banned in all current national laws, although this in no way eliminates the fact that the interruption or non-commencement of apparent life-giving treatment is an extremely complex matter.

An alternative decision, which is common to all the aforementioned situations, is to accept the risk of having children with hereditary malformations. In any case, increased knowledge in this field has opened the door to renewed discussions of negative eugenics (contraception, sterilization, and abortion) and of the limits to reproduction. However, this criterion is not incompatible with extensive health information on such matters which will help responsible decisions as to motherhood/fatherhood to be made.

CONCLUSION

The aim of this chapter is to briefly show the sensitivity required in performing genetic counselling from an ethical point of view, and the responsibility of counsellors, both from an ethical and legal perspective. At the same time, I was able to confirm the interest of international bodies to protect the human rights involved. On the contrary, some countries' authorities have decided to take the opportunity offered by available genetic techniques to develop compulsory measures, which affect personal beliefs and individuals' private decisions regarding their own reproduction. Whether this is, or is not, appropriate is open to future discussions.

NOTES

1. Law on the Protection of Maternal and Child Health, October 27, 1994: "Couples seeking a marriage license shall furnish the corresponding premarital medical examination of medical evaluation certificates" (Art. 12).
2. The Convention was signed and ratified by Spain on November 24, 1977, and October 1979, respectively.
3. Art. 10: "(Private life and the right to information). 1. Everyone has the right to respect for private life in relation to information about his or her health. 2. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed. 3. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient."
4. See Recommendation R (90) 13, on prenatal genetic screening, prenatal genetic diagnosis and associated genetic counselling (Principle 8).
5. An issue similar to the first point (possible criminal or civil liability as a result of inadequate weighing up of risks and advantages) will be addressed below in relation to amniocentesis, although this presents greater risks. The second point is important and arises in virtually all health-related fields, affecting economic policy and public health care priorities.
6. On this, see Council of Europe Recommendation R (90) 13, principle 10.
7. Jacques Testart (1994, 95) argues that, for these reasons, the technique should not be permitted.
8. Law 35/1988 of 22 November, on Techniques of Assisted Reproduction, art. 12.1: "All interventions on live, *in vitro* embryos for diagnostic purposes shall aim solely to assess their viability or otherwise, to detect hereditary diseases so as to treat them where possible or to advise against transfer for procreation." See also art. 8.2.a of Spanish Law 42/1988, on the use of human embryos and foetuses.
9. In France, Law 94-654 of 29 July 1994, on the donation and use of elements and products of the human body, medical assistance for procreation and prenatal diagnosis, lays down stricter criteria: "Biological diagnosis undertaken with cells taken from an *in vitro* embryo shall be authorized exceptionally in the following conditions: a practicing physician in a multidisciplinary centre for prenatal diagnosis, as defined in art. L. 162-16, must certify that the couple, in view of family circumstances, is highly likely to give birth to a child with a particularly serious genetic disorder which is acknowledged as being incurable at the time of diagnosis. The diagnosis may be made only where the abnormality or abnormalities of a similar disorder have been identified precisely and

previously in one of the parents. Diagnosis shall have the sole purpose of investigating this affection and the means of prevention and treatment. It may be undertaken only in a centre which has been specifically authorized following the opinion of the national committee on medicine, reproduction biology and prenatal diagnosis, and under the conditions defined by Council of State Medicine.

[10] Act NR 56, of 5 August 1994, on biotechnological applications in medicine.

[11] In conformity with art. 8.2a, Law 42/1988, cited previously.

[12] See Walters (1982, 489). The author argues that a health care system that caters extensively for prenatal diagnosis and abortion, but which has few services for the handicapped, could well influence considerably a couple's decision as to whether or not abort.

[13] France's Law 94-654 permits prenatal diagnosis in art. L. 162-16, while in the new drafting of art. L. 162-16 reference is made to the diagnosis in relation to interruption of pregnancy.

[14] Under art. 19: "A possible termination of the pregnancy or a ligature operation must be agreed to and signed by the person concerned. If said person does not have legal capacity to take the decision, the guardian shall agree and sign. Medical services shall be provided free of charge to any woman who has to terminate her pregnancy or undergo a ligature in accordance with the provision of this law."

[15] According to articles 16 and 20 respectively. Art. 16: "if a doctor detects of suspects that a married couple able to have children suffers from a serious genetic disease, he shall give guidance to the couple, who will take the appropriate measures in the light of the guidance received"; art. 20: "Prior to a second pregnancy, a woman who has given birth to a child with a serious malformation shall together with her husband, undergo a medical examination in a medical or health care institution in her province or residence or higher administrative level."

[16] A different situation arises in the case of a couple or mother not meeting these requirements (or not having the mental capacity) to take on full responsibility for having children.

[17] In effect, in certain cultures the preference for male children ahead of girls for economic reasons (the males being considered still more productive, because they enter the labor market earlier, whereas to marry off a girl the family requires a minimum amount of money for the dowry) has been aggravated by the indirect restriction on exceeding a given number of children (one in China). Hence, the prohibition of prenatal diagnosis aimed at revealing the sex of the child, save for the purpose of preventing gender-related disease.

[18] France's Law 94-654, in art. L. 162-16, makes it compulsory for prenatal diagnosis to be preceded by a genetic counselling session with the physician.

[19] Council of Europe Recommendation (90) 13: "The counsellor should under no condition try to impose his or her convictions on the persons being counselled, but inform and advise them on pertinent facts and choices" (principle 4).

[20] The International Association on Penal Law (1988, 1333), in its colloquy on *Criminal Law and Modern Biomedical Techniques*, rejected the use of prenatal diagnosis for the purposes of gender selection through abortion.

REFERENCES

Carrera, J.M. (1987) Diagnostico prenatal: un concepto en evolución, *Diagnostico Prenatal*, Salvat, Barcelona.

Egozcue, J. (1992) Diagnostico pre-conceptivo y preo-implantacional, in Palacios, M. (ed.), *Diagnostico prenatal y reproducción asistida*, Universidad de Cádiz-Ayuntamiento de San Roque.

Emaldi, A. (2001) *El consejo genético y sus implicaciones jurídicas*. Cátedra Interuniversitaria Fundación BBVA – Diputación Foral de Bizkaia, de Derecho y Genoma Human y Ed. Comares, Bilbao – Granada.

Eser, A. (1985) Genética humana desde la perspectiva del derecho alemán, *Anuario de Derecho Penal y Ciencias Penales* 351.

Esring, S.M. and Leonardi, D.E. (1985) Spontaneous abortion after amniocentosis in women with a history of spontaneous abortion. *Prenatal Diagnosis* 5, 321–8.

Fletcher, J. (1980) Knowledge, Risk and the Right to Reproduce. A Limiting Principle. In A. Milunsky and G. Annas (Eds.), *Genetics and the Law II.* Plenum Press, New York.

Fraser, F.C. (1980) Diagnostic prenatal des desordres genetiques, *Cahiers de Bioethique* 2.

Fuente, P. De la (1992) Diagnostico prenatal de las cromosomopatias, in Palacios, M. (ed.) *Diagnostico prenatal y reproducción asistida.* Universidad de Cádiz-Ayuntamiento de San Roque.

Guenther, H.L. (1987) Praenatale diagnose und pranatale therapie genetischer "defecte" aus strafrechtilicher sicht. In H.L. Gunther and R. Keller (eds.), *Fortpflanzungmedizin und Humangenetik. Strafrechtliche Schranken?* J.C.B. Mohr, Tubingen.

Hadjiminas, M. (1994) L'experience chypriote: depister pour combattre une maladie genetique grave. In Conseil de l'Europe (ed.), *Ethique et genetique humain*, Les editions du Conseil de l'Europe, Strasbourg.

Harichaux, M. (1992) Diagnostic prenatal: les obligations et les risques, in Gros, F. and Huber, J. (eds.), *Vers un antidestin? Patrimoine genetique et Droits de l'humanite*, Editions Odile Jacob, Paris.

Harper, P.S. (1990) Consejo Genético y diagnóstico prenatal, *Labor Hospitalaria* 218, 273.

International Association on Penal Law (1988) Criminal law and modern bio-medical techniques, *Revue Internationale de Droit Penal* 59, 1335.

Knight, L.A. and Mann, J. (1983) Maternal contamination in prenatal diagnosis. *Prenatal Diagnosis* 3, 155.

Lenoir, N. (1991) *Aux frontiers de la vie: un ethique biomedicale a la francaise*, La Documentation Francaise, Paris.

Montano, P.J. (1991) *La responsabilidad penal de médicos y científicos ante las nuevas tecnologías de la procreación*, Ediciones Jurídicas Amalio M. Fernández, Montevideo.

Nys, H., Romeo Casabona C.M., Desmet, C. (2002) Legal aspects of prenatal testing for late-onset neurological diseases. In Evers-Kiebooms, Zoeteweij, Harper (eds.), *Prenatal Testing for Late-onset Neurogenetic Diseases*, BIOS Scientific Publishers, Oxford.

Powledge, T.M and Fletcher, J. (1980) Recommendations concernant les problemes moraux, sociaux et juridiques relatifs au diagnostic prenatal, *Cahiers de Bioethique* 2, 92.

Rodotà, S. (1992) le Droit face aux dilemmas moraux de la vie et de la mort. In *XXth Colloquy on European Law*, Glasgow, 1990. Council of Europe, Strasbourg.

Romeo-Casabona, C. (1994) *El Derecho y la Bioética ante los limites de la vida humana*, Cera, Madrid.

_____ (1996) *Del gen al Derecho*. Universidad Externado de Colombia, Bogota.

_____ (1998) Health and Eugenic practices: Looking Towards the Future, *European Journal of Health Law*, 5, 3, 241.

_____ (2002) *Los genes y sus leyes. El Derecho ante el genoma humano*, Cátedra Interuniversitaria Fundación BBVA – Diputación Foral de Bizkaia, de Derecho y Genoma Human y Ed. Comares, Bilbao – Granada.

Shaw, M.W. (1984) Genetics and the law, *Encyclopedia of Bioethics*, 2nd Vol. McMillan and Free Press, New York.

Testart, J. (1994) *La procreación artificial*, Debate Dominos, Madrid.

Walters, L. (1982) ethical perspectives on maternal serum-alpha-fetoprotein screening, In Beaucham, T.L. and Walters, L. (eds.), *Contemporary Issues in Bioethics*, 2nd ed. Wadsworth Publishing Corp., Belmont.

Wertz, D.C., Fletcher, J.C., Berg, K., Boulyjenkov, V. (1995) *Guidelines on ethical issues in medical genetics and the provision of genetic services*, World Health Organization, Geneva.

ELISA J. GORDON

CHAPTER 17
INTERNATIONAL PERSPECTIVE ON ORGAN DONATION

INTRODUCTION

Countries worldwide suffer from the scarcity of organs for transplantation. Many more patients need organs for transplantation than are available through organ donation and the gap between supply and demand continues to widen. To increase the rate of organ donation, policy makers have looked toward increasing people's awareness of organ donation as well as implementing policies that are based on differing levels of autonomy.

Autonomy plays a key role in the transplant process. Its meaning, presence, or more aptly, its *absence,* significantly influences the process and rate of organ donation. Autonomy can be defined as "personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding" (Beauchamp and Childress 1994, 121). While autonomy relies upon the will of the individual, a "personal rule" may not be realized without the cooperation of others. Depending upon the culture, a cluster of donors, families, and transplant professionals must come to some agreement about removing organs from the deceased for the purpose of transplantation. That is, transplant professionals and lay people vary in how much they respect the wishes of the deceased about donation, and the salience of the family in decision making. Organ donation, particularly of cadaveric organs, is therefore a conspicuous forum for examining autonomous decision making. The availability of donors is thus contingent upon people's willingness to donate and upon the extent to which autonomous decisions are supported by family and physicians posthumously.

Several questions arise regarding the relationship between autonomy and organ donation. Why do others have the right to override an individual's autonomous decision to donate in different countries? Will policies and procedures that strive to increase organ donation rates be equally effective internationally? And, how does culture shape people's decisions about organ donation?

Using an anthropological perspective, this chapter explores why there is great variation in donation practices cross-culturally and why respect for individual autonomy is often not regarded in cadaveric donation. These issues will be addressed through an examination of culture-wide beliefs that influence people's attitudes toward organ donation and responses to legal policies on organ donation. This chapter reviews the empirical literature on actual donation decisions to ground our understanding of this diversity. After examining the diversity of attitudes about

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 235–255.

donation and its cultural foundations, this chapter concludes with a discussion of how policies can better account for cultural knowledge and practice to increase rates of organ donation. An international perspective is essential for illuminating how efforts to increase organ donation can be mediated by changes at the local, national, or cultural levels.

CROSS-CULTURAL ATTITUDES TOWARD ORGAN DONATION

A review of the empirical literature on organ donation cross-culturally reveals several themes about the cultural factors influencing people's attitudes toward donation. These include: (a) knowledge of organ donation, (b) definitions of brain death, (c) disposition of the body, (d) meaning of specific organs, (e) notions of altruism and gift-giving, (f) the role of the family, (g) uncertainty about religious perspectives, and (h) local concerns. Some of these themes are relevant on a broad, culture-wide level, while others are more specific to ethnic groups within a given culture. Many of these themes reveal how cultural values and contexts undermine or simply bypass the Western concept and ideal of individual rights in decisions about organ donation. As will become apparent, much of the previous research has been conducted in Asia and in the United States; the absence of studies within other regions and cultures of the world limits our understanding of attitudes about donation and our ability to address them appropriately in the international context.

Lack of Knowledge A relatively easily understood problem contributing to low donation rates worldwide is the lack of knowledge about organ donation and transplantation. For example, a public opinion poll of 520 citizens in Gallarate, Italy found that people were generally favorable to donation but had a superficial knowledge of the problem and relevant legislation (e.g., only 36% knew the difference between donation from a living or cadaver donor); the absence of correct information was considered the main cause of the scarcity of donations (Gerbino 1995). Ethnic groups, such as the Sikh community in the United Kingdom and the African American community in the United States, likewise have been reported to lack sufficient knowledge about organ donation and transplantation. Educational efforts have been directed toward the Asian and African American populations within the United States because of their especially high rates of end-stage renal disease (Callender et al. 1982; Exley et al. 1996). Confusion about Brain Death Another culture-related barrier to increasing organ donation is the concept of brain death. Definitions of death vary cross-culturally. The introduction of the Western definition of death as brain death to other countries has generated much confusion among people, regardless of culture or religion. Even health care professionals have reported confusion over definitions of death in the United States (Youngner et al. 1989). The willingness to donate is significantly affected by people's differing understandings or lack thereof of brain death as it is defined in the United States (Ad Hoc Committee 1968). People commonly express uncertainty about whether brain death really constitutes death. Will organs be removed from someone who is not 'really' dead yet? Confusion stems from the perception that even though patients are declared brain dead, they appear to be alive since they feel warm to the touch, *look as though they are asleep, and are still breathing with the aid of machines. Fears that patients are not really dead at the time of donation have been reported by many people surveyed, especially by members of diverse cultural groups, including Sikhs (Exley et al. 1996), Black South Africans (Kometsi and Louw 1999), and African Americans (Callender et al. 1982).* The lack of understanding about brain death is especially common in non-Western countries that have more recently introduced the technology and laws that enable organ donation to occur, and that are in the process of incorporating the concept of brain death into local meaning systems (Kaur 1998; Kometsi and Louw 1999). Some Black South Africans, for example, equated brain death with brain damage and expected such persons to be mentally and functionally impaired or disabled, rather than dead (Kometsi and Louw 1999).

Education, however, can facilitate people's acceptance of brain death and thus their willingness to donate. The usefulness of education was demonstrated when the willingness to donate increased from 76% to 89% after the concept of brain death was explained among high school students in Calabria, Italy (Roncone et al. 1996). In addition, a number of programs have been established to educate minorities about donation and transplantation within the United States, one of the most effective being the Minority Organ/Tissue Transplant Education Program (MOTTEP). MOTTEP has implemented community outreach programs that deliver messages through members of the community who are similar culturally to the groups being targeted, and through face-to-face presentations by transplant recipients and donors (Callender 1989). These organizations have successfully helped to raise awareness, educate, and dispel fears about donating among minority populations (Callender and Washington 1997).

Disposition of the Body Brain death, as it is defined in the US in accordance with efforts to procure organs for donation, is understood as a biological process marking the end of life. Death can also be seen as a social process, especially in non-Western populations, whereby aspects of a person continue to live on. It is this social component of death that underscores much of people's reluctance to donate organs. Specifically, people may believe that one's ancestors live on, so mutilating the body will interfere with a peaceful life after death for both the deceased and the living. This belief is shared by the Japanese and Chinese communities, though for different reasons. In Japan, many people object to organ donation because it violates Japanese Buddhist practices of ancestor worship (Lock 2002). Grounded in this Buddhist practice, deceased family members are transformed into ancestral spirits and must be respected and appeased (Lock 2002). Ancestors suffer (and consequently so does the extant family) if their corpses are left incomplete from organ donation. Similarly, cadaver donors are hard to find in China because of religious factors. Confucian beliefs, like the Japanese concept of filial piety, require relatives to return the deceased's body intact to the ancestors to traverse the underworld (Ikels 1997). Without their organs, ghosts may retaliate against those who authorized donation. In addition, ghosts do not rest until buried. But until that point, they remain in an agitated state amongst the living who may incur the wrath of the ghost (Ikels 1997). The belief in the existence of posthumous ancestors among Black South Africans also influences their decisions about donating. For these communities, donating an organ would mean that the deceased would become a complaining ancestor and thus persecute the living family because the body was not intact (Kometsi and Louw 1999).

Other people have also expressed related concerns about the integrity of the body for life after death. More African Americans and Hispanics than European Americans in the United States have been reluctant to grant permission to donate organs for religious beliefs that require “the body to be kept intact for life after death” (Callender et al. 1982; Creecy et al. 1992; Gallop Organization 1993; McNamara et al. 1999). Similarly, Sikhs in the United Kingdom fear that reincarnation would not be possible by tampering with certain organs or the body to prepare for the resurrection (Exley et al. 1996).

Alternatively, sociocultural beliefs and customs about the disposition of the corpse may influence people’s decisions to donate organs of deceased family members. For instance, the reasons why 24 people voluntarily chose to become organ or body donors in Greece were based largely upon personal and cultural understandings about the disposition of bodily “flesh” after death (Papagaroufali 1999). These donors feared being buried with its concomitant ritual exhumation and decomposition of fleshy parts. Donation provides a useful alternative because these respondents believe that immediately after death, the body is precious and semi-alive in its still fleshy state, and this state is immortalized through donation.

Meaning of Specific Organs People’s willingness to donate can also be related to the cultural and symbolic importance attributed to individual organs. For example, Chinese people may be reluctant to be living donors because of traditional Chinese notions of the role of the kidney in medicine (Ikels 1997). The kidney is believed to have multiple functions, some of which are associated with the nervous system. “Vital essence” or the “material basis of life” is stored in the kidney and can be transformed into qi, but its absence threatens the body’s structural and functional integrity (Ikels 1997:1275). Chinese and other Asians are also generally averse to accepting brain death and thus cadaveric donation, because of the belief that the heart is central to all life (Woo 1992; Ots 1994; Kaur 1998). In traditional Chinese medicine, the mind is located within the heart, which is understood as the seat of cognition and virtue, and is central to bodily and social well-being (Ots 1994).

Notions of Altruism and Gift-giving The reasons people provide for becoming living and cadaveric donors are not always altruistic in nature. Despite efforts of public policies to motivate altruism, people typically donate for other reasons, either because altruism-based policies do not accord with cultural traditions or for personal considerations (Sanner 1994; Siminoff and Chillag 1999). In Japan, for example, there is no tradition of altruism as there is in the United States (Lock and Honde 1990). Japanese social practices dictate that it is socially unacceptable to take things, i.e., organs, from others (Lock and Honde 1990). Since gift-giving in Japan is grounded in a framework of reciprocity, organ recipients are left in an *awkward situation because they are obligated to repay the cadaver donor but cannot (Lock 2002).* The range of personal reasons for donating are illustrated in the decisions of bone marrow donors in the United States, which include: an awareness of the benefits to the recipient, a desire to help another person, a desire to act in accordance with social and religious norms, and/or an expectation to experience positive feelings from donation and empathy for the recipient (Switzer et al. 1997).

Role of Family in Cadaveric Donation: Autonomy Challenged Regardless of legal policy (discussed below), physicians commonly ask families whether they would be willing to donate their deceased family member's organs (Wright 1998; Wendler and Dickert 2001). This practice entirely undermines an individual's autonomous decision as specified on a donor card. When donor cards are absent or donor wishes are unknown, family members serve as surrogate decision makers, aiding in extending the autonomy of the deceased. Still, this approach reflects a one-to-one relationship whereby a single individual can make a proxy decision on behalf of another. But in some non-Western cultures, where families play a significant role in individual identity and everyday life, this surrogate role may not be sufficient. For instance, among Black South Africans, there is not enough time to make a decision about donating because family members at the bedside must contact the entire family to make a decision: "the death of a member of a family is a concern of a group of people and not one or two individuals" (Kometsi and Louw 1999, 475). Similarly, since indigenous Omanis belong to a larger family group, neither a husband or wife can make a decision for a decedent regarding donation; rather, a decision must be made by the entire family, and disagreements are likely (Kehinde 1998). Policy makers in cultures such as these face the challenge of devising additional educational strategies and procurement procedures to ensure decision making by the entire family in a timely fashion. Uncertainty about Formal Religious Perspectives The reluctance or refusal to donate often stems from uncertainty about whether one's religion or religious leaders permit organ donation. This issue has been noted especially among Muslims, including Muslim South Asians from the Indian subcontinent living in the United Kingdom (Randhawa 1998; Ahmed et al. 1999), and Omanis who expressed confusion about the views of Islam on organ donation from cadavers (Kehinde 1998). Similarly, the Sikh community in the United Kingdom was unsure of Sikh positions on donation since there are no formal religious prohibitions against organ donation (Exley et al. 1996). Everyday, Locally Meaningful Concerns Locally significant circumstances unique to some subgroups are important factors influencing their attitudes toward donation. Several examples are readily available. Black South Africans have expressed reluctance to donate because death is associated with crime. They are concerned with the lack of justice for the many Black Africans who are killed and become potential donors (Kometsi and Louw 1999). Members of the Sikh community in the United Kingdom desire reassurance about the just allocation of organs since they worry that donated organs might go to those with the most money, which is common in India (Exley et al. 1996). Since expatriates come to work in Oman for pay, many express *willingness to donate based upon their ability to get money for their donations (Kehinde 1998). Numerous African Americans in the United States fear that once they sign a donor card, they will not receive proper care in a hospital and that their organs might be taken prematurely (Callender et al. 1982; McNamara et al. 1999). Their distrust of the medical establishment is based upon a history of enduring medical abuses, most notably, the Tuskegee medical experiments on black men in the 1950s and 1960s (Jones 1981; Dula 1994). Furthermore, Japanese resistance to organ donation and transplantation can be attributed to their reluctance to utilize imported transplant policies and technology because these are imbued with Western values of individualism and autonomy, which run counter to traditional Japanese cultural values of family (Lock 2002).* Although these specific examples vary dramatically owing to their different historical and social contexts, these groups share a status of being viewed as minorities when they are in countries other than their origin, and they may be vulnerable to the values of dominant others.

FOUNDATIONS OF DIVERSITY

In the section above, we can see exactly how cultural values and beliefs inform people's willingness to donate. And, actual decisions to donate go beyond the individual. Practical avenues toward success in organ donation require that policies and practices cohere with local cultural meaning systems. This is not a simple task; it entails a clear grasp of both: (a) fundamental cultural values and assumptions, usually tacitly held, and (b) exactly how these culturally shared beliefs inform diverse attitudes and approaches toward organ donation. Fundamental to cultural meaning systems is the concept of person. Conceptions of persons, as will be discussed below, are intertwined with the whole cultural matrix of beliefs about life, death, and the body, which are salient for organ donation. It is proposed here that policies designed to increase donation rates cross-culturally must address and incorporate locally meaningful conceptions of persons. However, many current donation policies, let alone the conception of organ donation as a desired act in itself, are based upon Western conceptions of persons as autonomous entities, as if autonomy were universally revered as it is in the United States, for instance. Thus attempts to implement Western policies in international settings are likely to encounter barriers to success.

Before examining the concept of person from a cross-cultural perspective, it is important to point out, however, that cultures are not static clusters of people who think and act the same exact way. Rather, cultures are constantly in flux and often beset with contradictory values and beliefs. With this in mind, the following discussion proposes two explanations for the culturally-based attitudes toward organ donation including, the concept of the person and notions of ownership of the body.

Concept of the Person Fundamental to people's attitudes toward organ donation is their concept of person and self. Personhood is how people define themselves as humans, and this definition varies cross-culturally (Shweder and Bourne 1984). More specifically, personhood can refer to a social "objectification of experiential processes" (Csordas 1994, 3) or, "how people actually represen[t] themselves to themselves and to one another it is a conception of what a human individual is" (Geertz 1984, 125–126). Personhood, or the perceived relationship between a person and their society, can be related to and even incorporate conceptions of selfhood, which can refer to reflexive self-awareness and self-identity (Smith 1985; Csordas 1994). While there are multiple scholarly definitions of conceptions of self and personhood, a useful framework for understanding the term is that culture provides orientations for people to structure their experience and understand others, such as through language, spatio-temporal frames of reference, and normative orientations (Hallowell 1955). These orientations are inherently symbolic or metaphorical (Smith 1985). An example relevant to the issue of autonomy is that time is conceived by Americans in the US in a linear fashion, as expressed through metaphoric idioms such as "time is money" and "wasting time" (Lakoff and Johnson 1980; Bergsma and Thomasma 2000). These metaphors convey the idea of a future-oriented conception of self that prompts people to make advance plans about their death, such as signing a donor card. Most cultures of the world maintain a holistic, sociocentric conception of person. The Oriya Indians and Chinese are such groups in that they define themselves through interactions and relationships with others (Shweder and Bourne 1984, 190–191; Hsu 1985, 27). In contrast, the dominant way in which many persons in Western cultures, especially the United States, conceive of themselves is as egocentric. The United States conception of the person is characterized as "a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment and action organized into a distinctive whole and set contrastively both against other such wholes and against a social and natural background" (Geertz 1984, 125). As such, Americans in the United States associate with a relatively limited range of intimate others; families are often nuclear rather than extended. The egocentric concept of self/person derives from the Cartesian dichotomy of mind and body. This is strongly expressed in the United States, where people emphasize their autonomy over their selves and bodies through individual rights, self-determination, and privacy (Barry 1988:1083). Similar to the distinction between sociocentric and egocentric selves is that between North European cultures which can be seen as a unitary "referential" entity and the contextually-based "indexical" self of Mediterranean or Latin European cultures (Gaines 1982, 181–186; Csordas 1994).

Besides the role of social others (as in sociocentric cultures), members of other cultures even incorporate into their conception of person other entities, such as spirits or animals. Among the Temiar of Malaysia, for instance, persons are composed of both a head soul and heart soul: the former is the seat of the animating aspect of life and conceptualized as a tiny manikin or cool flowing liquid, while the latter is the seat of thought and feeling, and is manifested as a tiger or odor or shadow; both souls can separate from the person while dreaming or ill (Roseman

1991). Not all human beings attain the status of persons (Csordas 1994). For instance, among poor Brazilians, whose children are highly malnourished and suffer a high infant mortality rate, newborns become considered as persons only when they have become old enough to overcome infection and stay alive (toddlers) (Scheper-Hughes 1990, 560).

The concept of the person and self is essential to understanding people's willingness to donate because organs are integral parts of the body, self, person, and identity. It is because family members are incorporated into individuals' conceptions of person that consent for donation becomes a family process. Ancestors play a pivotal role in people's willingness to donate cadaveric organs because spirits are included in people's notions of personhood. It is no wonder then, that among Westerners who typically maintain an egocentric concept of person, organs can be relatively easily donated after death, without concern for the impact of this act upon others or their posthumous selves. Conversely, the fact that autonomy is not ingrained in many non-Western cultures' conceptions of personhood reflects just how culturally based the construct and practice of organ donation is.

Concept of the Body: Ownership Another important factor influencing organ donation on both individual and national levels is how the body is conceptualized in terms of ownership. Ownership can mean several things, such as the commercialization of body parts for organ trade (which is beyond the scope of this paper). For the purpose of this discussion, "ownership" describes the rights of the entity who or that has the authority to make decisions about the disposition of the body. Is it up to the individual, the family, the state, or non-mortals? In the United States, autonomy is prioritized as the most important principle of ethics, and so self-determination and individual rights are legally established and culturally prized. Legally, people have a negative right to be free from interference with their body. It is proposed here that some Americans interpret this legal precedent to mean that individuals have a positive "right" to do what they wish to their own body, such as selling their organs or body parts (Marshall et al. 1996). Yet despite legal attempts to facilitate organ donation and respect the wishes of individual donors, e.g., via organ donor cards and presumed consent laws, physicians cross-culturally often give families the authority to make final decisions about the disposition of the body, even over the wishes of the donor. Physicians report that they involve families in such situations because they: (a) express respect for family in time of grief, (b) need to obtain a medical and social history, (c) fear bad publicity, and (d) fear being sued (Wright 1998; Wendler and Dickert 2001). As well, physicians may be uncomfortable with going against family wishes (Caplan 1984). In contrast to individual and familial authority, in China, the body of executed prisoners belongs to the state; therefore consent for donation is not sought (Woo 1992; Ikels 1997).

Transplant policies and practices must also take into account that there are subtle ways in which organs are owned (at least temporarily) by others at the regional level. For instance, in the US, transplant centers maintain the view that they are "stewards" of organs, and as such, seek to ensure that donated organs are transplanted to the most appropriate match (Gordon 2000). This suggests some element of control over the disposition of body parts though, of course, after they have been procured. This concept of stewardship is historically grounded in Christian religious thought (Campbell 1992), and figures centrally in a recent debate in the United States regarding the geographic distribution of organs. The United States Secretary of Health and Human Services, Donna Shalala, proposed a policy in 1998 that requires organs to be sent to the best match in the country, instead of within the local network. According to this policy, the organs procured locally often get sent outside of the network to other states. This proposal is controversial because transplant centers, professionals, as well as lay people, come to think of the organs procured within their network as “theirs” to use, at least to try to match with potential recipients locally first, before sending outside of their network if no suitable match can be found (Milford 1998; Ubel 1998). This situation is not unique to the United States; it occurs in Italy as well. Most transplant centers in Italy are located in the Northern provinces. Northern transplant centers tend to not perform transplants for Southern Italians because of the shortage of organ donors, preferring instead that the organs go to Northern Italians (Roncone et al. 1996). This form of discrimination is considered by Southern Italians as unethical and unlawful by undermining equal treatment to all Italians (Roncone et al. 1996).

Notions of organ ownership influence how members of cultures manage human body parts. These notions of ownership or autonomy regarding organ disposition extend beyond the individual to even encompass geographic regions. The nature of the agency that “owns” organs influences how different regions within countries confront the dilemma of fairly distributing organs for transplantation. Both conceptions of person and ownership of organs must be taken into consideration when devising policies to increase donation rates in culturally and ethically appropriate ways.

POLICIES TO INCREASE ORGAN “DONATION” RATES

With the growing international recognition of the serious need to increase the number of organ donors worldwide, scholars have proposed different methods to address this problem. Legal policies are the primary means to increase organ donation rates since they are designed to fully respect individuals’ autonomous decisions about organ donation. Yet policies and educational campaigns have had limited success worldwide partly because they are embedded with Western conceptions of autonomy. Autonomy is neither a universally recognized moral principle, nor does it carry the same valence cross-culturally as some scholars (philosophers and ethicists) assume (Marshall and Koenig 1996). As well, autonomy is a cultural construct informed by gendered assumptions about persons (Sherwin 1992).

Several types of policies have been proposed or implemented to increase the rate of cadaveric organ donation. These policies differ with regard to how much they respect the autonomy of individuals as active or passive agents in decision making about donation. Policies include definitions of death, voluntary or “opting in” efforts like required request and the use of organ donor cards, or “opting out” efforts like presumed consent (see Table 1). Some of these policies have been implemented in

Table 1. Approximate Organ Donation Rates Worldwide (Cadaveric)[1]

Country	Year data	Actual donors per million pop. (pmp)	Legislation	Legal Definition of of Brain Death
Spain	1998	31.5	Presumed Consent	Yes
USA	1998	22.7	Opt In	Yes
Austria	1998	20.8	Presumed Consent	Yes
Finland	1998	19.8	Presumed Consent	Yes
Belgium	1998	19.4	Presumed Consent	Yes
Czech Rep.	1998	19.2		
Luxembourg	1998	17.5		
France	1998	16.8	Presumed Consent	Yes
Portugal	1998	16.7		
Norway	1998	15.6	Presumed Consent	Yes
Switzerland	1998	15.4		
Sweden	1998	14.6		
Slovenia	1998	13.5		
Germany	1998	13.4	Opt In	Yes
UK-Ireland	1998	13.5	Opt In	Yes
The Netherlands	1998	13.1		
Italy	1998	12.3	Presumed Consent	Yes
Hungary	1998	12.2		
Denmark	1998	11.0	Presumed Consent	Yes
Australia	1998	10.5		
Latvia	1998	10.4		
Southern Israel[2]	1990-95	7.5		
Poland	1998	7.5		
Greece	1998	5.7	Opt In	Yes
Croatia	1998	4.7		
Lithuania	1998	3.6		
China				No
Singapore[3]	1991		Presumed Consent	Yes
Japan				Partial

[1] Source: Unless specified, all data on donations are from the European Transplant Coordinators Organization

[2] Source: Fisher et al. (1996)

[3] Source: Woo (1992).

different countries with varying success. The extent to which these policies are carried into practice and actually increase donation rates depends, to a large degree, upon the local cultural values of the hospital or nation.

Perhaps the most important policy influencing the practice of organ donation is the legal definition of death. Defining death as brain death, or the irreversible cessation of brain functioning, is necessary for the procurement of cadaveric organs. Otherwise, the increasing warm ischemic time following the heart and lung definition of death renders organs useless. Definitions of death therefore have a significant impact upon the source of donor organs. Countries with a legal definition of brain death procure more organs from cadaver donors than from living donors; the reverse holds true in countries without a legal definition of brain death, which is the case in most South American and Asian countries (Chugh and Jha 1995). Japan's definition of death, for example, is in the midst of reformulation: a new middle ground has been reached between respecting traditional values and increasing donor organs. Specifically, brain death can only be declared when a person had expressed a desire to donate prior to death, otherwise death is declared when the heart stops beating (McConnell 1999).

The process of “opting in” is illustrated well by the *Uniform Anatomical Gift Act* (UAGA) of 1984 in the United States. The UAGA requires that consent be obtained before organs can be removed from someone who has died. Consent may be obtained through organ donor cards or though surviving family members of the deceased. The use of organ donor cards has met with mixed success worldwide. For instance, public opinion polls in the United States have shown that people are generally in support of organ donation; approximately 50% of the general population is willing to donate their own organs and 53% would donate organs of a relative (Manninen and Evans 1985; Evans 1990; Gallop Organization 1993). The number of people who carry a donor card is relatively low in other countries: in the United Kingdom, 25% of the general population surveyed carried a donor card in 1984 (Lewis and Snell 1986). South Asians in the United Kingdom carried fewer cards than the general population in 1999 (16% vs. 28%) (Ahmed et al.1999). Besides donor cards, legal policy in the United States mandates that for hospitals to maintain accreditation, transplant coordinators must request donation from families of potential organ donors. Although health care professionals involved in organ procurement adhere to this legislation, organ donation rates remain low because fewer families consent to donate than previously expected (Siminoff et al. 1995), owing in part to problems with the request process itself (Siminoff et al. 2001, 2003; Verble and Worth 2003).

By these tokens, regardless of the presence of donor cards, patient autonomy is curtailed. Because of cultural beliefs and practices that ultimately involve others in the donation decision, donor cards are less useful in respecting autonomy than originally intended. Family wishes all too often trump those of the deceased. In recognition of these limits of donor cards, public educational campaigns in the United States have sought to encourage discussions about organ donation among family members.

Presumed consent or “opting out” procurement procedures assume that individuals wish to donate unless they specify otherwise through a national registry. Paradoxically, this policy circumvents the potential of family members to override the deceased’s prior autonomous decisions to donate, yet does so at the expense of limiting individuals’ autonomy by presuming that they intend to donate. No policy in practice can therefore be said to respect people’s free and authentic autonomous decisions. But the value of each policy can be measured by its impact on the organ donation rate, rather than its relationship to autonomy.

Opting out policies generally respect individual autonomy less than opting in policies because they require individuals to actively register their desire not to donate should they not wish to do so, rather than simply facilitate individuals’ desire to donate. Because giving one’s organs posthumously is essentially a requirement under this system, rather than an act of altruism, the term “donation” does not accurately describe the procurement processes in the international context. The concept of organ “donation” is predicated on altruistic norms and values as derived from Judeo-Christian religious traditions that may not be culturally relevant in non-American or non-Western cultures (Sharp 1995). Attention to the experiential basis of giving organs and the terminology used to describe the process may facilitate the development of effective procurement policies that better accommodate the values of the local culture.

The data appear contradictory as to the impact of the opting out system on increasing donor rates. Organ donor rates have been shown to be higher in countries with a system of presumed consent (e.g., Belgium, Austria, France, Singapore) than in countries with an opting in system (e.g., Germany, the United Kingdom, and the Netherlands) (Roels et al. 1990; Soh and Lim 1992). A study of five countries using different systems within the cross-national organ procurement network, Eurotransplant, found the opting out system to be more optimal than the opting in system (Kokkedee 1992). Other studies show that presumed consent has had little effect upon increasing organ donation rates (Land and Cohen 1992). The variation in success may be related to the fact that presumed consent may manifest itself in a strong or weak format. In its weak form, physicians typically consult with the family before procuring organs, as in France and Spain (Caplan 1984; Prottas 1985, 101; Lopez-Navidad et al. 1997).

Although the ethics of presumed consent have been explored considerably in literature, briefly, the primary concern with the policy is that individual preferences regarding donation will be ignored. Certainly, to ensure that individual autonomy or cross-cultural preferences regarding the disposition of the dead body be respected, educational campaigns that inform people of their rights to opt out through registering an objection to donation must be well-established (Council on Ethical and Judicial Affairs 1994). Suggestions for culturally-harmonic educational efforts will be presented in the concluding section.

Nevertheless, presuming that individuals make decisions on their own behalf remains a limitation of these policies to increase donation rates. Some cultural groups engage in the process of decision making differently than by those in Western countries. Anthropological studies of informed consent for genetic epidemiological research on hypertension, diabetes, and breast cancer in Nigeria show how decisions are initially made by community leaders and tribal elders (Marshall 2000). Policy makers must take into consideration the fact that the kinds of policies discussed above might not be readily adopted within cultures such as in Nigeria where decision making occurs on a group basis.

CULTURE CHANGE FOR A BETTER DONATION RATE

Policy makers cannot simply assume that even by addressing conceptions of personhood and notions of ownership of bodies, policies and educational efforts will be effective in changing views about organ donation. This is because cultures consist of a matrix of moral values embedded in the worldviews and practices of its members. To accent one moral value, e.g., altruism, over another will not necessarily work in improving donation rates given its relation to so many other aspects of a cultural system. One adjustment has a rippling effect throughout a culture, and may conflict with associated values. But this is not to say that cultures do not change. Significant cultural changes in regard to organ donation have occurred over the past decade and illustrate well how measures that addressed diverse aspects of culture effectively mobilized donation rates. Such changes have been made on different cultural and organizational levels.

For example, Spain's organ donation rate jumped from 14.2 per million population (pmp) in 1989 to 27 pmp in 1995 (Matesanz et al. 1996). Spain's status as the world leader in organ donation and transplantation is based upon the development of its National Transplant Organization (ONT), a decentralized network of medical and nursing staff committed to working throughout the organ donation and transplantation process (Matesanz and Miranda 1996). The ONT is also engaged in facilitating positive public attitudes about organ donation, a 24-hour transplant "hot line", and effective communication with the media (Bosch 1999). The ONT established guidelines for the content of messages about transplantation to provide to the media (Matesanz 1996). These include: (a) clear, concise, and well-argued messages, (b) consistency in manner of presentation of information, (c) always providing positive messages, (d) encouraging participation by the population in a common undertaking, e.g., donation, (e) specializing in the message of donation, (f) avoiding contradictory information, (g) avoiding conflicting topics such as doubt about brain death, (h) highlighting a unified organizational system, and (i) making clear distinctions between local situations and other regions or countries (Matesanz 1996). Other transplant organizations could benefit from incorporating some of these strategies, though they may need to be revised to better address the local cultural context.

Another example of how policies have effectively mobilized cultural systems to increase donation rates relates to the racial/ethnic background of transplant coordinators in the United States. Since the majority of transplant coordinators have been of European American descent, they tended to not have an ethnically sensitive approach to educating African American potential organ donor families (Callender et al. 1982). The predominantly European American hospital staff often hesitates to approach potential African American donor families because they are uncomfortable and unfamiliar with how African American families react to tragedy (Perez et al. 1988; Reitz and Callender 1993; Guadagnoli et al. 1999). African Americans' grieving behavior tends to be more demonstrative and dramatic (Hines 1991; Perry 1993) than that by some groups of European Americans who are characteristically stoic, e.g., Irish Americans (McGoldrick 1991) and White Anglo Saxon Protestants (McGoldrick et al. 1991). Hesitant organ procurement personnel have tended to "'overselect out' black families" because they assume such families will refuse to donate given their low donation rate (Prottas 1983, 294). To address these problems, hospitals and organ procurement organizations are now increasingly hiring organ procurement personnel of diverse ethnic backgrounds. This practice has helped to improve the rate of contact with minority family members and increase organ donation rates (Callender et al. 1991; Verble and Worth 2003).

Another illustration of culture change that increases donation rates is spurious events of cultural salience, as when foreigners die and donate organs in other countries. A striking case is that of Nicholas Green, an American seven year old boy traveling with his family on a vacation in Southern Italy, who was shot to death by Italian bandits in 1994. His parents donated his organs without hesitation: Nicholas's heart, liver, kidneys, pancreas, and eyes were donated to seven Italian youths around the country. This event raised national consciousness about the problem of organ scarcity in Italy. In fact, Italians responded with shock and "shame" to what they perceived as "strange generosity" in light of the violent circumstances. The emotional responses to the episode are worth noting because of the impact the event had on Italy's donation rate thereafter. Statements conveying these sentiments include: "The killing has inspired a remarkable display of soul-searching among Italians seized by what one newspaper called 'our shame'" (Cowell 1994, A1). Gregorio Botta, a columnist for the Italian newspaper, *La Repubblica*, reported: "Perhaps they do not realize how rare that gesture is in our country. Perhaps they do not realize that half the children with heart ailments in Italy do not make it and die while awaiting a transplant" (Cowell 1994, A1). The Italians perceived the donation as an honorable gesture because the Greens did not hold bitterness against them. This strong respect for the Greens was expressed through a ceremony where Italy's President Oscar Luigi Scalfaro offered the Greens a medal of honor. Italy's consul general in San Francisco, Giulio Prigioni, later told the Greens that "You have made a miracle" referring to the fact that the organ donation rate in Italy increased by 400 percent in the days following Nicholas' death (People Magazine, October 24, 1994,64).

Was Nicholas' story a unique account or would this event have had the same type of impact elsewhere, particularly where the donation rate is still relatively low? As a matter of fact, the parents of a five-year old American boy living in Japan decided to donate his organs upon his death from a simple fall *(Nephrology News and Issues* 1997; *People Magazine* 1996). As with the case of Nicholas, this incident has had a tremendous impact upon organ donation in Japan. After transplanting organs into two Japanese patients, 4,000 Japanese doctors reported that they would start a campaign to encourage donation by families of brain-dead patients (*People Magazine* 1996). This event has also influenced the Japanese government to legalize a modified version of brain death (*Nephrology News and Issues* 1997).

PROPOSALS FOR OVERCOMING BARRIERS TO ORGAN DONATION

Much of this chapter is predicated on the assumption that organ donation is a good practice because it helps to save lives. It is worth questioning whether organ donation is a universally good practice in light of the broad range of cultural traditions that find donation difficult to accept and integrate into their cultural worldviews. A universal approach to mitigate the scarcity of organs for transplantation is therefore unlikely to be broadly accepted given the diversity of attitudes toward organ donation. It is not difficult to understand why non-Western cultures are resistant to organ donation because Western cultural values are embedded in the technology and ideology surrounding transplantation (Gordon 1988; Lock 2002). Such values may clash with those in other cultures, as in the case of Japan discussed above.

To take another example, the "gift of life" metaphor promoted by United States transplant professionals has even had a negative impact upon American recipients and donors (Siminoff and Chillag 1999). This metaphor is used to help recipients adjust to their new organs and lifestyle by promoting the biomedical view that organ donation is an altruistic, selfless act requiring no reciprocity (Joralemon 1995; Sharp 1995; Siminoff and Chillag 1999). Yet transplant professionals' efforts to maintain distance between recipients and donors are undermined when recipients wish to get to know donor families to express their gratitude for the "gift of life." The "gift of life" metaphor can be detrimental to donor families and recipients because it reinforces the gift-giving bind and disregard of recipients' quality of life post transplant (Fox and Swazey 1992, 207). Even in India where donors can be paid, the gift-giving bind exacts a greater toll on recipients in that they feel "forever 'in debt,'" since expectations of reciprocity remain following the exchange of the commodity of a human body part (Marshall and Daar 2000).

The value that other cultures place upon organ donation and transplantation may differ from that in the United States and other Western countries. American cultural factors such as the technological imperative and ethos of denial of death embedded in American biomedicine also help to drive the transplantation and donation process forward (Fuchs 1968; Fox and Lipton 1983; Callahan 1993). We should take pause and assess whether interests in keeping only some of the world's people alive, the underlying values driving the interest in increasing donation rates, and the methods of doing so are priorities equally shared by others within a culture and by other cultures. Organ transplantation has assumed a priority in the United States over other health conditions: end-stage renal disease patients are entitled to treatment although many more poor people have no access to primary care. This is a stark consideration, though there may be other values at stake besides life itself, like economic motivations (Rettig 1991).

This kind of self-reflection is necessary when seeking to address ethical dilemmas from a cross-cultural perspective. It is through self-reflection that we gain some modicum of mental distance to determine the potential impact of one set of values upon other people. This thought process is important to engage in also because we must be careful to not impose our ethical principles upon other cultures – especially when they "make sense" – otherwise doing so constitutes a form of moral imperialism (Angell 1988, 1082).

Yet even if we consider the possibility of cultures uniformly favoring organ donation, it is still imperative to assess the basis for that uniformity. Put differently, the universality of a belief does not constitute "rightness." As anthropologists have shown, there may be different cultural value systems and mechanisms that generate such universal practices, but which in themselves are not necessarily esteemed as "good" or "right" in other cultures (Ortner 1974). The purpose of raising this possibility is to question the end goal of universally encouraging organ donation, and to problematize the perceived problem of diversity in attitudes toward organ donation.

To illustrate this concern, we can turn to cross-cultural patterns in living donation. More commonly than not, females donate their organs to males, whether it be mothers or daughters donating to sons or brothers or husbands, in Hong Kong (Hawkins 1996), India (Singh et al. 1998), Iran (Khajehdehi 1999), and in the US (Bloembergen et al. 1996; Gordon 2001). The predominance of female donors in Asian countries is based upon the greater cultural value placed on males than females, and on the female role to serve males (Hawkins 1996). By encouraging members of all cultures to donate, do we unwittingly promote gender discrimination? The concern that wives are being coerced to donate to their husbands in India is so strong that a policy has been established requiring a minimum of five years of marriage before living donation is permitted (Singh et al. 1998). Similarly, in Iran, most living non-related donors, who are female, donate out of need for money (Khajehdehi 1999). This raises the specter of exploitation among those most vulnerable in society.

Out of respect for the diversity of attitudes toward organ donation, it is not necessarily the intention of the author to propose *normative* guidelines on the best way to increase rates of organ donation worldwide. Instead, an international perspective helps to inform our ideas about useful strategies to facilitate organ donation endeavors with attention to how such proposals would resonate within different cultural contexts. It is proposed here, albeit with some caution, that education campaigns tailored to the concerns and needs of specific local cultural groups, can be effective mechanisms that can both respect the values of such groups and coincide with myriad aspects of cultural world-views. To avoid the situation of imposing one value set upon another, educational campaigns must ensure that their content and presentation account for local concepts of the person which are central to people's attitudes about death and organ donation.

Educational efforts are certainly worthwhile to inform and clarify misconceptions about organ donation, the definitions of death, the process of procurement, bodily integrity for burial, and legal and hospital policies, among other issues. Based on a review of the literature about willingness to donate discussed above, attempts to educate people would likely be most effective if they focused on the meaning of brain death. Yet, attempts that encourage greater discussion about end-of-life issues may be less successful for cultural groups that devalue discussing bad news or death e.g., the Navajo in the US (Carrese and Rhodes 1995), or feel uncomfortable engaging in such discussions e.g., Hispanics (McNamara et al. 1999). Educators must also be aware that formal public educational efforts may be less effective than transmitting information through informal networks, which occurs among the United Kingdom's South Asian population (Khan and Randhawa 1999). For instance, members of the Sikh community in the United Kingdom reported that educational efforts could be improved through providing information to *Gurdwaras* or religious temples which often serve as community centers. In addition, information about organ donation should be presented in languages spoken by all citizens within a country, not just the dominant language. Further, information should be conveyed through different formats. To take the Sikh community in the United Kingdom again as an example, they reported that effective communication would entail both written literature in Punjabi, and oral, face-to-face presentations for those who are less literate, such as the elderly (Exley et al. 1996).

But education can only go so far (Perez et al. 1988). It should be pointed out that some scholars (who tend to not be social scientists) tend to construe what are in fact fundamental cultural understandings as "misconceptions" that can be clarified by education. This way of thinking presumes that deeply seated systems of values and beliefs can change by way of education and that behaviors can be modified by increasing people's knowledge base (Good 1994). Yet even when people have greater or more accurate knowledge about brain death, they may be less willing to donate than are those with less knowledge (Horton and Horton 1991; McNamara et al. 1999). To some extent, information can have a positive impact upon people in terms of donating, though because cultural values, beliefs, and systems of morality are deeply ingrained into people's worldview and bodily practices, educational efforts may be limited in their capacity to significantly change donation practices among diverse cultural groups. Educational campaigns, health policies and other efforts to increase donation rates must contend with different cultural contexts and conceptions of autonomy to be effective.

REFERENCES

Anonymous. (1984) Landmark article Aug 5, 1968: A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *Journal of the American Medical Association,* 255, 677–679.

Ahmed, W., Harris, S. and Brown, E. (1999) Attitudes to organ donation among South Asians in an English high street. *Journal of the Royal Society of Medicine,* 92, 626–627.

Angell, M. (1988). Ethical imperialism? Ethics in international collaborative clinical research. *New England Journal of Medicine,* 319, 1081–1083.

Barry, M. (1988). Ethical considerations of human investigation in developing countries: the AIDS dilemma. *New England Journal of Medicine,* 319, 1083–1086.

Beauchamp, T.L. and Childress, J.F. (1994). *Principles of Biomedical Ethics* (4th ed.). New York: Oxford University Press.

Bergsma, J. and Thomasma, D.C. (2000). *Autonomy and Clinical Medicine: Renewing the Health Professional Relation with the Patient.* Boston/Dordecht/London: Kluwer Academic Publishers,

Bloembergen, W.E., Port, F.K., Mauger, E.A., et al. (1996). Gender discrepancies in living related renal transplant donors and recipients. *Journal of the American Society of Nephrology,* 7, 1139–1144.

Bosch, X. (1999). Spain leads world in organ donation and transplantation. *Journal of the American Medical Association,* 282, 17.

Callahan, D. (1993). *The Troubled Dream of Life: Living with Mortality.* New York: Simon and Schuster.

Callender, C.O., Bayton, J.A., Yeager, C. and Clark, J.E. (1982). Attitudes among Blacks toward donating kidneys for transplantation: A pilot project. *Journal of the National Medical Association,* 74, 807–809.

Callender, C.O., Hall, L.E., Yeager, C.L., et al. (1991). Organ donation and Blacks: A critical frontier. *New England Journal of Medicine,* 325, 442–444.

Callender, C.O. and Washington, A.W. (1997). Organ/tissue donation the problem! Education the solution: A review. *Journal of the National Medical Association,* 89, 689–693.

Campbell, C. (1992). Body, self, and the property paradigm. *Hastings Center Report,* Sept–October, 34–42.

Caplan, A.L. (1984). Organ procurement: It's not in the cards. *Hastings Center Report,* October, 9–12.

Carrese, J.A. and Rhodes, L.A. (1995). Western bioethics on the Navajo reservation. *Journal of the American Medical Association,* 274, 826–829.

Chugh, K. S. and Jha, V. (1995). Differences in the care of ESRD patients worldwide: Required resources and future outlook. *Kidney International*, 48, S7–S13.

Council on Ethical and Judicial Affairs, American Medical Association. (1994). Strategies for cadaveric organ procurement: Mandated choice and presumed consent. *Journal of the American Medical Association,* 272, 809–812.

Cowell, A. (1994, October 4). Italy moved by boy's killing and the grace of his parents. *The New York Times,* p. A1, A6.

Creecy, R.F., Wright, R. and Berg, W.E. (1992). Discriminators of willingness to consider cadaveric kidney donation among black Americans. *Social Work in Health Care*,18, 93–105.

Csordas, T.J. (1994). Self and Person. In P.K. Bock (ed.), *Handbook of Psychological Anthropology.* Westport: Greenwood Publishing Group.

Dula, A. (1994). African American suspicion of the healthcare system is justified: What do we do about it?" *Cambridge Quarterly of Healthcare Ethics,* 3, 347–357.

Evans, R.W. (1990). The Actual and Potential Supply of Organ Donors in the United States. In P. Terasaki (ed.), *Clinical Transplants*. Los Angeles: UCLA Tissue Typing Laboratory.

Exley, C., Sim, J., Reid, N., et al. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: A pilot study. *Social Science and Medicine,* 43, 23–28.

Fisher, A., Herzog, L.J.P. and Herzog, E.M. (1996). Five years' experience of an organ donation team in southern Israel. *Israel Journal of Medicine and Science,* 32, 1112–1119.

Fox, M. and Lipton, H.L. (1983). The decision to perform cardiopulmonary resuscitation. *New England Journal of Medicine,* 309, 607–608.

_____. (1992). *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press.

Fuchs, V. (1968). The growing demand for medical care. *New England Journal of Medicine,* 179, 190–195.

Gaines, A.D. (1982). Cultural Definitions, the Person, and Behaviour in American Psychiatry. In A. Marsella & G. White (eds.), *Cultural Conceptions of Mental Health and Therapy*. Dordrecht: D. Reidell.

The Gallop Organization, Inc. (1993). *The American Public's Attitudes Toward Organ Donation and Transplantation*. Boston: The Partnership for Organ Donation.

Geertz, C. (1984). 'From the Native's Point of View': On the Nature of Anthropological Understanding. In R.A. Shweder & R.A. LeVine (eds.), *Culture Theory: Essays on Mind, Self, and Emotion*. Cambridge: Cambridge University Press.

Gerbino, P. (1995). Opinione Pubblica e Trapianti: I Risultati di Un Indagine. (Public opinion and transplantation: Results of a survey). *Rivista Dell Infermiere,* 14, 67–70.

Good, B.J. (1994). *Medicine, Rationality, and Experience*. Cambridge: Cambridge University Press.

Gordon, D.R. (1988). Tenacious Assumptions in Western Medicine. In M. Lock & D.R. Gordon (eds.), *Biomedicine Examined.* Dordrecht/Boston/London: Kluwer Academic Publishers.

Gordon, E.J. (2000). Preventing waste: A ritual analysis of candidate selection for kidney transplantation. *Anthropology & Medicine*, 7, 351–372.

Gordon, E.J. (2001). "They don't have to suffer for me": Why dialysis patients refuse offers of living donor kidneys. *Medical Anthropology Quarterly*, 15, 1–22.

Guadagnoli, E., McNamara, P., Evanisko, M.J., et al. (1999). The influence of race on approaching families for organ donation and their decision to donate. *American Journal of Public Health*, 89, 244–247.

Hallowell, A.I. (1955). The Self in it's Behavioural Environment. *Culture, Personality, and Experience*. Philadelphia: University of Pennsylvania Press.

Hawkins, B.R. (1996). Current status of organ transplantation in Hong Kong. *Transplantation Proceedings*, 28, 1190–1192.

Hines, P.M. (1991). Death and African-American Culture. In F. Walsh & M. McGoldrick (eds.), *Living Beyond Loss: Death in the Family*. New York: W.W. Norton & Co.

Horton, R.L. and Horton, P.J. (1991). A model of willingness to become a potential organ donor. *Social Science and Medicine*, 33, 1037–1051.

Hsu, F.L.K. (1985). The Chinese Self. In G. DeVos, A. Marsella & F. Hsu (eds.), *Culture and Self: Asian and Western Perspectives*. New York: Tavistock.

Ikels, C. (1997). Kidney failure and transplantation in China. *Social Science and Medicine*, 44, 1271–1283.

Jones, J. (1981). *Bad Blood: The Tuskegee Syphilis Experiment*. New York: The Free Press.

Joralemon, D. (1995). Organ wars: The battle for body parts. *Medical Anthropology Quarterly*, 9, 335–356.

Kaur, M. (1998). Organ donation and transplantation in Singapore. *Transplantation Proceedings*, 30, 3631–2632.

Kehinde, E.O. (1998). Attitude to cadaveric organ donation in Oman: Preliminary report. *Transplantation Proceedings*, 30, 3624–3625.

Khajehdehi, P. (1999). Living non-related *versus* related renal transplantation – its relationship to the social status, age and gender of recipients and donors. *Nephrology Dialysis Transplantation*, 14, 2621–2624.

Khan, Z. and Randhawa, G. (1999). Informing the UK's South Asian communities on organ donation and Transplantation. *EDTNA ERCA J*, 25, 12–14.

Kokkedee, W. (1992). Kidney procurement policies in the Eurotransplant region: 'Opting in' versus 'opting out.' *Social Science and Medicine*, 35, 177–182.

Kometsi, K.J. and Louw, J. (1999). Deciding on cadaveric organ donation in Black African families. *Clinical Transplantation*, 13, 473–478.

Lakoff, G. and Johnson, M. (1980). *Metaphors We Live By*. Chicago: University of Chicago Press.

Land, W. and Cohen, B. (1992). Postmortem and living organ donation in Europe: Transplant laws and activities. *Transplantation Proceedings*, 24, 2165–2167.

Lewis, A. and Snell, M. (1986). Increasing kidney transplantation in Britain: The importance of donor cards, public opinion and medical practice. *Social Science and Medicine*, 22, 1075–1080.

_____. (1995). Contesting the natural in Japan: Moral dilemmas and technologies of dying. *Culture, Medicine and Psychiatry*, 19, 1–38.

Lock, M. (1996). Deadly Disputes: Ideologies and Brain Death in Japan. In S. Youngner, R. Fox & L. O'Connell (eds.), Organ *Transplantation: Meanings and Realities*. Madison: University of Wisconsin Press.

_____. (2002). *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.

Lock, M. and Honde, C. (1990). Reaching Consensus About Death: Heart Transplants and Cultural Identity in Japan. In G. Weisz (ed.), *Social Science Perspectives on Medical Ethics*. Philadelphia: University of Pennsylvania Press.

Lopez-Navidad, A., Domingo, P. and Viedma, M.A. (1997). Professional characteristics of the transplant coordinator. *Transplantation Proceedings*, 29, 1607–1613.

Manninen, D.L. and Evans, R.W. (1985). Public attitudes and behaviour regarding organ donation. *Journal of the American Medical Association*, 253, 3111–3115.

Marshall, P.A. (2000). Multinational empirical bioethics research. *Panel at the American Society for Bioethics and Humanities*. October 26–29.

Marshall, P.A. and Daar, A. (2000). Ethical Issues in Human Organ Replacement: A Case Study from India. In L.M. Whiteford & L. Manderson (ed.), *Global Health Policy, Local Realities: The Fallacy of the Level Playing Field*. Boulder: Lynne Publishers, Inc.

Marshall, P.A. and Koenig, B.A. (1996). Bioethics in Anthropology: Perspectives on Culture, Medicine, and Morality. In C.F. Sargent & T.F. Johnson (eds.), Medical *Anthropology: Contemporary Theory and Method*, Revised Edition. Westport: Praeger.

Marshall, P.A., Thomasma, D.C. and Daar, A. (1996). Marketing human organs: The autonomy paradox. *Theoretical Medicine*, 17, 1–18.

Matesanz, R. (1996). Transplantation and the Mass Media. In R. Matesanz & B. Miranda (eds.), *Organ Donation for Transplantation: The Spanish Model*. Madrid: Grupo Aula Medica.

Matesanz, R. and Miranda, B. (1996). Organ donation – the role of the media and of public opinion. *Nephrology*, *Dialysis*, *Transplantation*, 11, 2127–2128.

Matesanz, R. and Miranda, B. (1996). *Organ Donation for Transplantation: The Spanish Model*. Madrid: Grupo Aula Medica.

Matesanz, R., Felipe, C., Fernández, M. and Miranda, B. (1996). Introduction. In R. Matesanz & B. Miranda (eds.), *Organ Donation for Transplantation: The Spanish Model*. Madrid: Grupo Aula Medica.

McConnell, J.R. (1999). The ambiguity about death in Japan: An ethical implication for organ procurement. *Journal of Medical Ethics*, 25, 322–324.

McGoldrick, M. (1991). Irish families. In F. Walsh & M. McGoldrick (eds.), *Living Beyond Loss: Death in the Family*. New York: W.W. Norton & Co.

McNamara, P., Guadagnoli, E., Evanisko, M.J., et al. (1999). Correlates of support for organ donation among three ethnic groups. *Clinical Transplantation*, 13, 45–50.

Milford, E.L. (1998). Organ transplantation – barriers, outcomes, and evolving policies. *Journal of the American Medical Association*, 280, 1184–1185.

Nephrology News and Issues. (1997). The death of an American boy is changing minds on organ donation in Japan. *Nephrology News and Issues*, 11, no. 1.

Ortner, S.B. (1974). Is Female to Male as Nature is to Culture? In M. Rosaldo & L. Lamphere (eds.), *Woman*, *Culture and Society*. Chicago: Stanford University Press.

Ots, T. (1994). The Silenced Body – The Expressive *Leib*: On the Dialectic of Mind and Life in Chinese Cathartic Healing. In T.J. Csordas (ed.), *Embodiment and Experience*. Cambridge: Cambridge University Press.

Papagaroufali, E. (1999). Donation of human organs or bodies after death: A cultural phenomenology of 'flesh' in the Greek context. *Ethos*, 27, 283–314.

People Magazine. (1994). The gifts of Nicholas: Italian bandits snuff out an American boy's life but not his legacy of hope. *People Magazine*, 24, 61–64.

_____. (1996). Gift of Hope. *People Magazine*, 9, 111–112.

Perez, L.M., Schulman, B., Davis, F., et al. (1988). Organ donation in three major American cities with large Latino and black populations. *Transplantation*, 46, 553–557.

Perry, H.L. (1993). Mourning and Funeral Customs of African Americans. In K.F. Lundquist & V.J. Nelson (eds.), *Ethnic Variations in Dying*, *Death*, *and Grief: Diversity in Universality*. Washington: Taylor & Francis.

_____. (1985). Procurement in Europe and the United States. *Milbank Memorial Fund Quarterly*, 63, 94–126.

_____. (1986). In organ transplants, Americans first? Commentary. *Hastings Center Report*, 16, 23–25.

Randhawa, G. (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian Population in Luton, UK. *Nephrology*, *Dialysis and Transplantation*, 13, 1949–1954.

Reitz, N.N. and Callender, C.O. (1993). Organ donation in the African-American population: A fresh perspective with a simple solution. *Journal of the National Medical Association*, 85, 353–358.

Rettig, R.A. (1991). Origins of the Medicare Kidney Disease Entitlement: The Social Security Amendments of 1972. In K. Hanna (ed.), *Biomedical Politics*. Washington: National Academy Press.

Roels, L.,Vanrenterghem, Y., Waer, M., et al. (1990). Effect of a presumed consent law on organ retrieval in Belgium. *Transplantation Proceedings*, 22, 2078–2079.

Roncone, A.,Vantaggiato, A., Benevenuto, A., et al. (1996). Organ procurement: Experience from a southern Italian region. *Transplantation Proceedings*, 28, 239–241.

Roseman, M. (1991). *Healing Sounds from the Malaysian Rainforest: Temiar Music and Medicine*. Berkeley: University of California Press.

Sanner, M. (1994). Attitudes toward organ donation and transplantation: A model for understanding reactions to medical procedures after death. *Social Science and Medicine*, 38, 1141–1152.

Scheper-Hughes, N. (1990). Mother Love and Child Death in Northeast Brazil. In J. Stigler, R. Shweder & G. Herdt (eds.), *Cultural Psychology: Essays on Comparative Human Development*. Cambridge: Cambridge University Press.

Sharp, L.A. (1995). Organ transplantation as a transformative experience: Anthropological insights into the restructuring of the self. *Medical Anthropology Quarterly*, 9, 357–389.

Sherwin, S. (1992). *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia: Temple University Press.

Shweder, R.A. and Bourne, E.J. (1984). Does the Concept of Person Vary Cross-Culturally? In A.J. Marsella & G.M. White (eds.), *Cultural Conceptions of Mental Health and Therapy*. Boston: D. Reidel Publishing Company.

Siminoff, L.A. and Chillag, K. (1999). The fallacy of the 'gift of life.' *Hastings Center Report*, November, 34–41.

Siminoff, L.A., Arnold, R.M., Caplan, A.L., et al. (1995). Public policy governing organ and tissue procurement in the United States. *Annals of Internal Medicine*, 123, 10–17.

Siminoff, L.A., Gordon, N., Hewlett, J. and Arnold, R.M. (2001). Factors influencing families' consent for donation of solid organs for transplantation. *Journal of the American Medical Association*, 286, 71–77.

Siminoff, L.A., Lawrence, R.H. and Arnold, R.M. (2003). Comparison of black and white families' experiences and perceptions regarding organ donation requests. *Critical Care Medicine*, 31, 146–151.

Singh, P., Srivastava, A. and Kumar, A. (1998). Current status of transplant coordination and organ donation in India. *Transplantation Proceedings*, 20, 3627–3628.

Smith, B.M. (1985). The Metaphorical Basis of Selfhood. In G. DeVos, A. Marsella & F. Hsu (eds.), *Culture and Self: Asian and Western Perspectives*. New York: Tavistock.

Soh, P. and Lim, S.M.L. (1992). Opting-out law: A model for Asia – The Singapore experience. *Transplantation Proceedings*, 24, 1337.

Switzer, G.E., Dew, M.A., Butterworth, V.A., et al. (1997). Understanding donors' motivations: A study of unrelated bone marrow donors. *Social Science and Medicine*, 45, 137–147.

Ubel, P. (1998). Geographic favouritism in liver transplantation – Unfortunate or unfair? *New England Journal of Medicine*, 339, 1322–1325.

Veatch, R.M. (1984). Autonomy's temporary triumph. *Hastings Center Report*, October, 38–40.

Verble, M. and Worth, J. (2003). Cultural sensitivity in the donation discussion. *Progress in Transplantation*, 13, 33–37.

Wendler, D. and Dickert, N. (2001). The consent process for cadaveric organ procurement: How does it work? How can it be improved? *Journal of the American Medical Association*, 285, 329–333.

Woo, K.T. (1992). Social and cultural aspects of organ donation in Asia. *Annals of the Academy of Medicine*, *Singapore*, 21, 421–427.

Wright, D.H. (1998). Survey report: Advance directives and donor card effectiveness, 1998. Council on Organ Availability Donor Card Survey, UNOS. UNOS, Richmond, VA. Retrieved July 6, 1998 from http://www.unos.org.

Youngner, S.J., Landefeld, C.S., Coulton, C.J., et al. (1989). 'Brain death' and organ retrieval: A cross-sectional survey of knowledge and concepts among health professionals. *Journal of the American Medical Association*, 261, 15, 2205–2210.

ROSAMOND RHODES

CHAPTER 18
JUSTICE IN THE DISTRIBUTION OF TRANSPLANT ORGANS*

The remarkable success of solid organ transplantation over the past two decades has exacerbated the demand for transplant organs. Improved survival rates have encouraged more patients to pursue transplantation as the most effective treatment for end-stage organ failure and have persuaded doctors to look to transplantation as innovative therapy for a broader range of lethal medical conditions. Furthermore, because transplanted organs frequently have to be replaced after a period of successful function, transplant recipients outlive the viability of their transplanted organs and eventually require re-transplantation. All tolled, the demand for organs has increased dramatically while the number of organs donated for transplantation has increased only slightly year by year. The number of cadaveric organs donated for transplantation is not large enough to meet the growing demand in spite of national and local efforts to boost organ donation. Currently in the United States, nearly 90,000 patients are waiting for a transplant organ. In the six month period from January – July 2005, 16,445 organ transplants were performed, 12,401 from deceased donors. (UNOS October 18, 2005). Still, about 6,000 Americans die each year for lack of a transplant organ (UNOS 2003). This severe shortage of human organs for transplantation has created competition for the cadaveric organs that are donated and made allocation policies highly controversial.

While many disparities in what people have and get are unavoidable, other disparities can be averted, and while many disparities are ethically unproblematic, others signal serious problems of injustice. David C. Thomasma appreciated the importance of justice considerations in the allocation of transplant organs and he devoted considerable attention to them throughout his career in bioethics. He wrote about issues of justice in transplant organ distribution, encouraged others to address them, and participated in some crucial discussions, including the conference that accompanied launching a national trial of liver allocation to carefully selected HIV positive patients with organ failure. David Thomasma relied upon Aristotle's insights in this domain as he did in so much of his work. He also called for "altruism and solidarity" as the crucial values for determining just policies (Thomasma 1992). In what follows, I shall accept David Thomasma's guidance in considering the requirements for justice in organ allocation.

---

* This paper draws on some of the material that I discussed in Rhodes R., Justice in Transplant Organ Allocation Policy, chapter in *Medicine and Social Justice: Essays on the Distribution of Health Care*, Rhodes, R, Battin, M.P. and Silvers, A (eds.), Oxford University Press. 2002: 345–361.

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 257–269.

JUSTICE

We learn from Aristotle, that social policies are just when they provide for equal treatment of all who are similarly situated and when they attend to relevant and important common human concerns (Aristotle 1971). Policies are unjust when they give priority to extraneous concerns and irrelevant differences and thereby give people in relevantly similar situations inequitable treatment.

Different people who might consider principles for making an equitable allocation of transplant organs could settle on a range of different guiding principles. When the "God Committees" of the early 1970s allocated the use of scarce dialysis equipment they scrutinized the lives of individuals with end-stage kidney failure to determine which candidates were most worthy of treatment. (Jonsen 1998). They considered individuals' past contribution to society, possible future contributions, family relationships, community evolvement, age, behavioural contribution to their disease, how badly off one person was relative to others, etc.

Such considerations are very appropriate to many decisions that we make every day about the distribution of limited resources. In awarding honours and prizes, we look to the record of people's previous achievements. In selecting grant recipients, we look to the significance and likelihood of future accomplishments. In making out a guest list for a party, we choose guests according to family lines, friendship, or other social ties. Being an upstanding member of the community may count when we choose representatives in political associations. Character may be an appropriate consideration in hiring decisions. Age as well as sex can count as a qualifying or disqualifying standard for a variety of activities such as athletic competition and membership in some social groups. Responsibility for a current condition can be a consideration in compensation and restitution. And how badly off one person is compared with others should count in the award of certain kinds of scholarships.

CLINICAL JUSTICE

Yet, the crucial question for the allocation of transplant organs is whether all of the standard array of considerations are appropriate for medical decisions. If we imagine a doctor in a crowded hospital emergency room, we immediately recognize that the range of appropriate principles for allocating the doctor's finite supply of energy, skills, time, and medical supplies is drastically restricted. We expect doctors to treat first those whose condition is most urgent, then to allocate the resources that they command according to need, and, ultimately, to treat everyone as equals in that doctors are expected to care about the well being of all of their patients. In situations of extreme scarcity, such as the aftermath of a cataclysmic disaster or on the battlefield, we accept that doctors will also consider efficacy. When faced with acutely insufficient resources, doctors are supposed to triage patients; they identify those who are most likely to require a significant investment of medical assets and least likely to derive significant benefit from them and assign them the lowest treatment priority with the expectation that many in that group will not survive. In the face of a drastic shortage we actually expect doctors to withhold treatment from some in order to avoid the worst outcome for the entire pool of patients. In sum, medicine recognizes only urgency, need, equality, and efficacy as appropriate principles for what I shall call "clinical justice." For the most part, society accepts those constraints as the appropriate standard for the distribution of medical resources and appreciates that allocations of medical resources according to those criteria are equitable.

In most cases, comparative appraisals of patients that go beyond the considerations of clinical justice are illegitimate for the allocation of medical resources. Thoughtful doctors are deeply distressed when other considerations (e.g., quality of life, money) are pressed upon them by unusual circumstances. Medicine is committed to the non-judgmental regard of every patient and a caring attitude toward each.

These are professional commitments because they have an essential role in promoting the community's trust. We all want our doctors not to judge us harshly and to take good care of us regardless of who we are and what we have done. We see this most dramatically in wartime when doctors are expected to treat all medically needy soldiers alike, those from their own army as well as enemy soldiers. Medicine's longstanding and implicit attachment to the limitations of clinical justice enables patients to bring themselves to doctors so that they can receive the benefits that medicine has to offer. We actually expect doctors to care for all who need medical attention without making judgments of worthiness and without applying criteria other than those of clinical justice.

CLINICAL JUSTICE IN TRANSPLANTATION

Without a strong and special justification for departing from the usual criteria of clinical justice, there is no reason to presume that considerations other than urgency, need, equality, and efficacy should play a role in the allocation of scarce transplant organs. Of these, the most appropriate considerations for distinguishing between potential recipients should be the urgency of patient need and the likelihood for success. Beyond those medical standards, patients should be treated equally (Rhodes et al. 1992).

Transplantation policies do not and should not treat all people equally: Everyone is not given equal access to organs for transplantation (e.g., one per person or an equal-sized piece to everyone). Transplant organs, which are especially scarce and precious resources, are reserved only for those who need them. Principles for their just distribution aim at achieving equity (rather than equality) by treating relevant differences among those who need a transplant similarly. Whereas there are many differences among candidates, the crucial policy problem becomes specification of the relevant differences and assignment of a relative priority to each of those relevant differences. When a policy gives irrelevant differences significant weight and when that assignment results in unequal treatment of similarly situated transplant candidates, the policy is, on its face, inequitable and, therein, unjust.

Furthermore, families that donate the organs of deceased loved ones do so out of appreciation of the great good that transplanted organs provide and out of trust that their gifts will be allocated justly. They expect that all those in need of organs will be treated equitably and that organs from deceased donors will be allocated according to principles that reasonable people could endorse. The entire enterprise of transplant surgery, including transplant centres, organ procurement organizations (OPOs), and the United Network for Organ Sharing (UNOS), expresses our society's acknowledgment of the great benefit that transplantation provides for those with end-stage organ failure and society's intention to equitably allocate its scarce transplant organs.

So far, transplant programs have largely treated non-medical judgments about patients as irrelevant differences and, for the most part, they resist the impulse to make blatant personal or relative judgments about recipient worthiness. These professional positions on the appropriate physician attitude toward patients have translated into the transplant community's reluctance to make judgments about potential recipients' worthiness, behavioural contribution to their present organ failure, or even the share of good life that the patient has already enjoyed (i.e., age).

By quantifying severity of disease and using those numbers as the basis for allocation decisions, UNOS can be seen as attempting to identify and to prioritize only medically relevant differences in need so that transplant candidates can be treated equitably. The system's stated aim is to establish instruments for making uniform measurement for urgency of need (i.e., "how *soon* someone will die without the transplant" and "how *badly off* someone will be without it") so that patients who are listed for transplantation at different centres can be fairly assessed and compared (Kamm 1993, 234). Although arguments persist about how much weight should be assigned to each consideration, the criteria are intended to reflect differences in urgency of need and they can be validated with clinical data and adjusted to reflect refinement in outcome prediction. While the specific criteria and standards vary somewhat from organ to organ, (because of immunological sensitivities and features specific to the survival of particular organs), these assessment instruments are supposed to quantify medical differences and, beyond these relatively objective criteria, to leave priority to fairness as approximated by a rule of first-come-first-serve.

LIVER ALLOCATION POLICY

The criteria developed for the distribution of livers from cadaveric donors provides an instructive example. The Adult Donor Liver Allocation Algorithm (Table 1) along with the Child-Pugh score (Table 2) for listing liver transplant candidates were developed to approximate an objective standard for the assessment of potential recipients and for the allocation of organs based on the seriousness of need and urgency. Using these systems, candidates for liver transplantation are assigned points based on their symptoms and biological markers of disease. Patients with liver disease must have 7 points to be listed for transplantation. Then, depending on the number of points their condition merits and factors about their disease, they are assigned to a category of urgency (e.g., 1, 2A, 2B, 3). Theoretically, those with the most urgent need are given priority for receiving an organ. Organs are also matched to recipients based on biological and size compatibility so as to minimize harm and to maximize benefit.

After working with the Child-Pugh scoring system for a number of years and collecting data on patient survival, the OPTN/ UNOS Board of Directors proposed a new system for liver allocation to more closely approximate justice in the allocation of livers for transplantation. The Model for End Stage Liver Disease (MELD) plan went into effect on February 27, 2002. It assigns points to different indicators of serious liver of disease and thus provides a number that is intended to represent each potential recipient's urgency of need. (Table 3) The MELD system was promoted because it is supposed to make the assessment of urgency more objective than the

Child-Pugh scoring system so as to allow those in most urgent need to have priority in the allocation of cadaveric livers. Waiting time, which had previously played a significant role in allocation, would only be used to break a tie in MELD scores.

Table 1. Adult Donor Liver Allocation Algorithm

Points	1	2	3
Encephalopathy	None	1–2	3–4
Ascites	Absent	Slight (or controlled by diuretics)	At least moderate despite diuretic treatment
Bilirubin (mg/dl)	<2	2–3	>3
Albumin (g/dl)	>3.5	2.8–3.5	<2.8
INR	<1.7	1.7–2.3	>2.3

United Network for Organ Sharing (September 4, 2001)
Available at http://www.unos.org/frame_Default.asp?Category=aboutpolicies.

Table 2. Child Turcotte-Pugh (CTP) Scoring System to Assess Severity of Liver Disease Points

MELD = (0.957 X LN (cratinine) + 0.378 X LN (bilirubin) + 1.12 X LN (INR) + 0.643)

Available at http://www.optn.org/AR2003/chapter_X_AR_CD.htm.

The MELD system relies upon studies of individual indicators of the seriousness of disease. Liver disease is very complicated and the assessment of urgency is very difficult. Individual markers of serious disease might turn out to be more or less significant in the light of additional indicators. The system therefore includes a modification mechanism that can be used to correct the intuitive weights assigned to individual factors or their numerical addition in order to allow the MELD system even more accurately to reflect differences in urgency even more accurately.

TRANSPLANT POLICY GOALS

In general, society expects that the focus on the good of patients is the central moral goal of medicine. In transplantation, society expects that the commitment to the good of individual patients and the good of the pool of potential transplant recipients is the guiding agenda in the establishment of organ transplant programs and the design of equitable organ allocation policies. Individuals each have their own unique conceptions of what is good. Nevertheless, because human beings have common needs, there is a significant overlap in their appreciation of what counts as good. It is reasonable to presume that everyone who is a candidate for an organ transplant sees life, the ability to function, the enjoyment of liberty and pleasure, and the avoidance of pain as good (Gert et al. 1998). To the extent that receiving a transplant is necessary for their enjoyment of all of these most important goods, it seems reasonable to presume that people who need an organ transplant in order to live, or to live without significant disability, most of all want transplant policies to provide them with the best chance of getting an organ that functions well. It is also reasonable to presume that those with a loved one who is a transplant candidate and those who can imagine themselves or a loved one someday being a transplant candidate would also consider receiving a successful transplant as the primary goal for organ transplant policy. Since policies are just when they attend to people equitably with respect to their most important human concerns, policies that govern allocation of vital organs for transplantation must give priority to what is most important to potential recipients. The primary good that a just policy must provide is a transplant organ, and, in the face of the current shortage of transplant organs, the good that policies should promote is the increased likelihood of receiving an organ and having a successful transplant.

This is not to say that other things are not important to transplant candidates as well. Candidates will want transplant policies and programs to provide respectful treatment, caring attention, honest and clear communication, clean and attractive surroundings, and convenience. These various considerations will have different priorities for different individuals; some factors will be significant to some patients and trivial to others. Yet, it is hard to imagine that receiving an organ and having a successful transplant is not the first priority of organ transplant candidates with respect to transplant programs and policies. Indeed, when patients understand the differences among transplant centres and have the option, we see them flocking to programs with a proven track record of success or travelling to be listed in regions where they are more likely to receive an organ (UPMC 1997). In life, when different options offer opportunities for satisfying different preferences, people make choices and they triage their values so they can achieve what is most important to them. Various considerations have different weight in different contexts and what is less important is sacrificed for the sake of achieving what is most crucial.

So, while having a transplant centre close to home may be important to some patients, it is easy to appreciate that they might be willing to travel farther for the sake of achieving other more important goals. Because of the priority that most accord to receiving an organ and having a successful transplant, reasonable transplant candidates would be likely to endorse policies that tend to increase organ availability and to improve the likelihood of transplant success over policies that provide greater convenience, particularly if that convenience should cost organs.

EFFICACY

In addition to the urgency of need, listing criteria have focused on the medical judgment of likelihood of efficacy. Policies for organ distribution take the limitations of cold ischemic time into account in order to maximize organ viability. Programs also evaluate patients for the likelihood of their long-term survival and the likelihood of post-transplant organ survival. When a potential recipient becomes so ill that the likelihood of survival is significantly diminished, the patient is not listed for transplantation or is made inactive on the UNOS organ recipient list.

Patients are also evaluated with respect to the likelihood of adhering to rigorous post-transplant protocols so that the transplanted organ will not be lost to rejection. Typically, when a patient's history raises questions about the likelihood of adherence with a schedule of anti-rejection medications and post-transplantation medical monitoring, the patient is further examined and assessed by a psychiatrist or a social worker. Adherence and efficacy are reasonable and relevant medical considerations for the evaluation of individual patients because cadaveric organs are scarce and they should be allocated so as to provide significant benefit.

DISPARITIES AND UNSUPPORTED DISTINCTIONS

A careful examination of UNOS allocation policies, however, reveals that additional agendas inform some of their positions and practices. Although UNOS policies are supposed to provide for the just allocation of cadaveric transplant organs, and while they take significant steps in that direction, UNOS policies still have some way to go in achieving justice. There are several ways in which UNOS policy falls short of the mark.

In her June 1, 1998 letter to Congress, Donna Shalala, then Secretary of Health and Human Services, discussed a significant problem in the way organs are allocated for transplantation in the United States. Describing the effects of the UNOS policy, she explained that,

> The median waiting times for the two major liver transplant centres in Kentucky were vastly different–38 days at one centre, 226 at the other. Similarly, in Louisiana, the median waiting time at one centre was reported to be 18 days, while at another, it was 262 days. In Michigan, the numbers were 161 days and 401 days. Although these numbers do not tell the whole story, they certainly reflect that unacceptable disparities in waiting times exist, even within States (Shalala 1998).

While many disparities in what people have and what they get are unavoidable, other disparities can be averted, and while many disparities are ethically unproblematic, others signal serious problems of injustice. In that UNOS policies create a disparity in waiting times for transplantation, require some groups of patients to meet standards that are not applied to others, and treat groups with similarly need for a transplant organ differently, current policies raise the question of injustice. Transplant policy distinctions that rest on claims about inferior efficacy of transplantation for a group of patients must be supported by compelling evidence of shorter graft or patient survival in that group. Differentiation in listing, prioritization, or allocation of organs without an adequate basis of evidence should be eyed with suspicion and distinctions based on unsupported assumptions should be presumed to create injustice.

Comparing UNOS policies to the medical literature reveals that some are not supported by evidence. Some policies appear to reflect distinctions that fall outside the domain of clinical justice. Consider, for example, some of the liver transplant policies that are now in effect. Regardless of the urgency of their need or the likelihood of their future adherence to post-transplantation regimens, UNOS policy requires at least six months of abstinence before patients with a history of drug or alcohol use can be listed for liver transplantation. Although this may seem like a reasonable requirement, for patients who have less than six months of life expectancy, this rule can make the difference between eligibility for transplantation and life or ineligibility for transplantation and death.

UNOS's six month rule relies on the presumption that patients who are "substance abusers," alcohol and narcotics users in particular, are at greater risk of non-adherence and losing transplanted organs than other patients. Without evidence of low efficacy for transplantation of former alcohol and drug users, the listing of these patients is restricted by a waiting period and requirements for participation in abstinence support programs. Similar requirements are not applied to other patients who may have ignored medical advice to lose weight, to stop smoking cigarettes, to restrict their diet, or to have regular follow-up visits with medical specialists. At the same time, evidence suggests that patients who have been substance abusers but who are otherwise judged likely to comply with post-transplant regimens do adhere to their required post-transplant treatment. They maintain their transplanted organs as well as other carefully selected patients, even though some organ recipients do resume some substance use post-transplant at a lower than pre-transplant level. (Osorio et al. 1994; Gerhardt et al. 1996; Tang et al. 1998; Burra et al. 2000; Pereira et al. 2000; Mackie et al. 2001).

Distinguishing between patients in the face of refuted presumptions is ethically untenable: presumptions that persist, in the face of counter-evidence smack of unfounded discrimination. Without evidence of a difference in outcomes, holding patients with a history of alcohol or narcotics use to a different standard from others is not medically justified. The social stigma associated with alcohol and narcotics suggests that illegitimate judgments of patient worthiness have been introduced into these policies and considerations beyond the limits of clinical justice have been incorporated into these UNOS policies.

Similarly, the 1996 rule change (implemented in 1998) that gave priority to status 1 liver transplant patients (people who suddenly develop liver failure and are likely to die within a week) over status 2A patients (people with chronic liver failure who have deteriorated to the point where they are likely to die within a week) raises questions of evidence and justice. The argument for the rule change was that patients with chronic illness (status 2A patients) had a lower chance of surviving than patients with acute liver failure (status 1 patients) who had otherwise been healthy. The implicit justification was that the change in policy would allow more people to benefit from transplantation (Showstack et al. 1999). Yet, opponents of the change have argued that the data does not support the distinction. If that claim is true, the change in policy unjustly disadvantages those with chronic illness. In either case, such distinctions in patient treatment are only justified by a significant difference in efficacy. Until a significant disparity in outcomes can be shown, allocation policy should not distinguish between potential recipients. Hunches are not enough of a ground for medical judgment, and assumptions cannot support policy distinctions for allocation of life-preserving scarce resources. As Frances Kamm has argued, very small differences may not be significant enough to justify a distinction that will leave some to die while others live or suffer a major disability (Kamm, 2002).

Another set of questionable efficacy claims are invoked to support local priority in organ distribution. Advocates of such policies claim that by keeping organs within a local or regional geographic area they can be transplanted when they are more viable and, thereby, improve outcomes. They also claim that because local priority policy has the consequence of transplanting organs to patients who are less seriously ill in some regions, patient survival in those areas is improved. Again, current evidence does not support these conclusions. Today's methods of organ preservation allow for longer periods of kidney and liver cold ischemia time than had been previously feasible without a diminution in organ viability (Stratta et al. 1990; Bretan 1994; Pirenne et al. 2001). Furthermore, geographic boundaries do not always translate into shorter transport times because the other side of the boundary could actually be closer or take less time to reach than the other side of the local sector. And, as to the question of an improvement in the number of patients who survive, the 1999 Institute of Medicine (IOM) report, *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule*, suggests the opposite. According to the IOM study,

> as OPO size increases to 9 million people, . . . the number of status 2B and 3 [less urgently ill] patients receiving transplant could be reduced to allow more status 1 and 2A [more urgently ill] patients to receive transplants, without an increase in pre-transplant mortality for the status 2B and 3 patients (IOM 1999, 70). [*Words in brackets added.*]

Advocates of local priority also maintain that keeping organs close to their source will increase donation, in other words, that people are more likely to donate organs to needy patients within the local OPO. Again, findings in the IOM study dispute these assumptions (IOM 1999, 47 and 71). Without strong evidence for a significant enough difference in outcomes, drawing geographic distinctions between potential organ recipients is unjust because geographic differences should be irrelevant to organ allocation.

Donna Shalala's declaration that the disparities in waiting time are "unacceptable" amounts to a charge of injustice. Robert M. Veatch, a former member of the UNOS Ethics Committee and author of *Transplantation Ethics*, echoes that assessment. According to Veatch,

> [t]he bottom line is that local priority makes the transplant program inequitable. People who are equally sick, who have equal entitlement to a transplant, and who are equally good candidates will have significantly different probabilities for getting an organ. Because many people die while on the waiting list, a delay in getting an organ equals an increased risk of death. The moral principle of justice requires that people who are equally situated are entitled [to] be treated equally (Veatch 2000, 375).

The IOM report acknowledges the problem of injustice but defines it in terms of disparities in life risk rather than variations in waiting time. According to the IOM analyses of available data, there is a 5% variation in the transplant rates for status 1 patients [acutely, urgently ill patients] in different OPOs, but a 13% variation for status 2B patients, and a 35% variation for status 3 patients. After discounting other factors that might contribute to the disparity, the IOM report authors cautiously conclude that, "smaller OPOs, by generally transplanting more status 2B and 3 patients [patients who are less urgently ill] than larger OPOs, may contribute to a situation in which more severely ill patients are required to wait longer for organs at increased risk of death" (IOM 1999, 73).

We recognize that preference for those who are near and dear is sometimes appropriate, but sometimes such distinctions are inadmissible. There are many situations in which it is perfectly acceptable to bestow favours on family and friends while we withhold them from others. When other reasonable people could not reasonably object to the preferential treatment, we allow priority for the near and dear as a morally acceptable consideration (Scanlon 1998, 158–171). Yet, the controversy over local priority and suspicion about the motives of its advocates suggest that people may have good reason for opposing local priority in organ distribution and that preference for those who are nearby may be inappropriate for a national organ allocation scheme. Organ distribution may require us to think instead in terms of altruism and solidarity.

Furthermore, laws and language that promote geographic localism are divisive and dangerous to a multi-cultural democratic society. Geographic localism undermines our national spirit of cooperative mutual support for fellow Americans in time of need, encourages prejudice and discrimination that is anathema to justice in allocation, and thwarts the good will of those good Samaritans who donate out of love for their neighbours. Nevertheless, laws recently passed in several states (e.g., Louisiana, Oklahoma, South Carolina, Wisconsin) prohibit organs from leaving the state if patients in the state could use them. These positions are supported by the rhetoric of local politicians and transplant officials. For example, Governor Frank Keating of Oklahoma has complained that the federal government tries to "suck organs" from his state and Nancy A. Kay, executive director of the South Carolina Organ Procurement Agency has declared that "Our work is based on the giving of South Carolinians. . . . We like to take care of our neighbours here" (Kay, 1998; Keating, 1998).

Current organ allocation policies that allow local priority in organ distribution make it more likely that patients in some regions will receive an organ when they are not urgently ill. Transplant centres in these regions prefer this arrangement because it allows them to transplant healthier patients who are likely to have an uncomplicated course. Yet, as the IOM report makes clear, the resulting disparity in treatment of similarly situated needy patients is unfair and, therein, a violation of justice (IOM 1999, 73).

CONCLUSION

Patients and the public are well served when they can feel secure that allocation of transplant organs is governed by just policy. While the UNOS principles declare a commitment to justice and objectives that are similar to those advocated in this paper, the subtly inserted extra added on agendas make a significant difference in the resulting allocation policies. Policies that distinguish between patients without evidence to support differences in transplant efficacy and policies that sacrifice fairness to local priority cannot be counted as just.

To achieve justice in transplant organ allocation, the patient's good must be clearly avowed as the guiding agenda in the establishment of organ transplant programs and the design of organ allocation policies. We must, therefore, focus policies on nurturing society's altruism and solidarity and creating a system that will maximize the chance of each recipient receiving a successful transplant. Policy makers must, therefore, commit themselves to treating patients with equity. They must be discriminating in their assessment of demands and refuse to be sidetracked by other irrelevant private agendas. They must also command and wield the authority to enforce just policies in order to allow the public to be confident that transplantation is a trustworthy part of medicine.

Local
1. Status 1 patients in descending point order

Regional
2. Status 1 patients in descending point order

Local
3. Status 2A patients in descending point order
4. Status 2B patients in descending point order
5. Status 3 patients in descending point order

Regional
6. Status 2A patients in descending point order
7. Status 2B patients in descending point order
8. Status 3 patients in descending point order

National
9. Status 1 patients in descending point order
10. Status 2A patients in descending point order
11. Status 2B patients in descending point order
12. Status 3 patients in descending point order

UNOS Policy 3.6 Allocation of Livers (June 16, 2000).
Available at http://www.unos.org/frame_Default.asp?Category=About.

REFERENCES

Aristotle. (1971) *The Nicomachean Ethics of Aristotle, Book V.*, Oxford University Press, London.

Bretan, P.N. (1994) Characterization of improved renal transplant preservation mechanisms using PB2 flush solution by HPLC assay. *Transplant International 7* Supplement1:S465–8.

Burra, P., Mioni, D., Cillo, U., Fagiuoli, S., Senzolo, M., Naccarato, R., Martines, D. (2000) Long-term medical and psycho-social evaluation of patients undergoing orthotopic liver transplantation for alcoholic liver disease. *Transplant International* 13 Supplement 1:S174–8.

Gerhardt, T.C., Goldstein, R.M., Urschel, H.C., Tripp. L.E., Levy, M.F., Husberg, B.S., Jennings, L.W., Gonwa, T.A., Klintmalm, G.B. (1996) Alcohol use following liver transplantation for alcoholic cirrhosis. *Transplantation* 62(8), 1060–3.

Gert, B., Clouser, K.D., Culver, C. (1998), *Bioethics: A Return to Fundamentals*, Oxford University Press.

Institute of Medicine (IOM) report (1999) *Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule*, National Academy Press, Washington, DC.

Jonsen, A.R. (1998) *The Birth of Bioethics*, Oxford University Press, New York.

Kamm, F.M. (1993) *Morality, Mortality: Volume I*, Oxford University Press, New York.

Kamm, F.M. (2002) Rhodes, Battin, and Silvers (eds.), *Health Care and Social Justice*, Oxford University Press, New York.

Kay, N.A. (1998) States Want to Keep Residents' Donated Organs: Supporters Say Local Patients Would Benefit, CNN *Interactive*(July 14) as posted at <

Keating, F. (1998) States Want to Keep Residents' Donated Organs: Supporters Say Local Patients Would Benefit, CNN *Interactive* (July 14) as posted at <http://cnn,com/HEALTH/9807/-14/keeping.organs.ap/index.html>.

Mackie, J., Groves, K., Hoyle, A., Garcia, C., Garcia, R., Gunson, B., Neuberger, J. (2001) Orthotopic liver transplantation for alcoholic liver disease: A retrospective analysis of survival, recidivism, and risk factors predisposing to recidivism. *Liver Transplant* 7(5), 418–27.

Osorio, R.W., Ascher, N.L., Avery, M., Bacchetti, P., Roberts, J.P., Lake, J.R. (1994) Predicting recidivism after orthotopic liver transplantation for alcoholic liver disease. *Hepatology* 20(1) Pt 1, 105–110.

Pereira, S.P., Howard, L.M., Muiesan, P., Rela, M., Heaton, N., Williams, R. (2000) Quality of life after liver transplantation for alcoholic liver disease. *Liver Transplant* 6(6), 762–68.

Pirenne, J., Van Gelder, F., Coosemans, W., Aerts, R., Gunson, B., Koshiba Fourneau, I., Mirza, D., Van Steenbergen, W., Fevery, J., Nevens, F., McMaster, P. (2001) Type of donor aortic preservation solution and not cold ischemia time is a major determination of biliary strictures after liver transplantation. *Liver Transplant* 7(6), 540–45.

Rhodes, R., Miller, C., Schwartz, M. (1992) Transplant Recipient Selection: Peacetime vs. Wartime Triage, *Cambridge Quarterly of Healthcare Ethics* 4(4), 327–331.

Scanlon, T.M. (1998) *What We Owe to Each Other*, The Belknap Press of Harvard University Press, Cambridge, MA.

Donna Shalala's Letter to Congress June 1, 1998.

Showstack, J., Katz, P.P., Lake, J.R., Brown, Jr, R.S., Dudley, R.A., Belle, S., Wiesner, R.H., Zetterman, R.K., Everhart, J. (1999) Resource utilization in liver transplantation: Effects of patient characteristics and clinical practice, *Journal of the American Medical Association* 281(15), 1381–86.

Stratta, R.J., Wood, R.P., Langnas, A.N., Duckworth, R.M., Markin, R.S., Marujo, W., Grazi, G.L., Saito, S., Dawidson, I., Rikkers, L.F. (1990) The impact of extended preservation on clinical liver transplantation, *Transplantation* 50(3), 438–43.

Tang, H., Boulton, R., Gunson, B., Hubscher, S., Neuberger, J. (1998) Patterns of alcohol consumption after liver transplantation, *Gut* 43(1), 140–45.

Thomasma, D.C. (1992) Ethical Issues and Transplantation Technology, *Cambridge Quarterly of Healthcare Ethics*, 4 (1), 333-343, 338.

United Network for Organ Sharing (UNOS), (2003) Annual Report to the U.S. Scientific Registry of Transplant Recipients and the Organ Procurement and Transplantation Network. http://www.optn.org/AR2003.

United Network for Organ Sharing, UNOS Critical Data (October 18, 2005). [available at http://www.unos.org/data.htm & http://www.unos.org/data/data_resources.asp]

UPMC News Bureau Release, (Nov. 18, 1997) Data Analysis Supports Idea of Broad Sharing of Donor Livers, available at <http://www.upmc.edu/NewsBureau/consad.htm> (Dec. 4, 1998).

Veatch, R.M. (2000) *Transplantation Ethics*, Georgetown University Press, Washington, DC.

ÁNGELA APARISI MIRALLES AND JOSÉ LÓPEZ GUZMÁN

CHAPTER 19
HUMAN CLONING AND HUMAN DIGNITY

INTRODUCTION

The advances that have been made in recent years in the field of genetics have been spectacular. Among them, experiments in cloning deserve special attention. The first successful experiments date back to the 1950s.[1] However, the most recent work carried out in this field has made it clear that it is possible to reach goals previously considered to belong to the realm of science-fiction.

As a result of the creation of the sheep Dolly in 1997, at the Roslin Institute in Scotland,[2] a social and ethical debate was re-ignited that had been started years before.[3] The controversy started when George Washington University announced, a few years previously, that it had managed, using the technique of cloning, to reproduce in the laboratory, from one human embryo, other embryos with the same genome.[4] However, unlike the project in February of 1997, this experiment did not come to term (i.e. no living creatures were produced).

The current debate, despite having its origins in the cloning of a mammal, has been centred almost exclusively on the problem of the moral and legal question of whether human cloning should be allowed (Pennisi 1997). Underlying the controversy is the widely held belief that human cloning will take place, that it is only a matter of time before it occurs (Lenoir 1998, 13).

Following the publication of the work carried out by Wilmut's team that resulted in the living Dolly, the serious moral issues that accompany the arrival of the treatment of human beings as instruments through their use in cloning, became repeatedly apparent in various cases and institutions.[5] The social pressure was so strong that even legal mechanisms were approved, with unusual speed, to impede such conduct.[6] These reactions were produced both at an international organisational level as well as that of the internal law systems of various countries (Williams 1997). Thus, for example, on March 18, 1997, the OMS (Organizzazione Mondialé della Sanitá) issued a *Declaration on Cloning* (1997). This organisation considers the use of cloning to reproduce human beings to be ethically unacceptable because it violates the dignity of a person, and the protection of the security of human genetic material.[7] The OMS based its declaration on the conclusions reached in 1992 by the scientific group created to study the technical aspects of medically assisted reproduction, within the *Program of research and development in human reproduction.* This group expressed the need to respect the indispensable freedom of scientific research. However, it also expressed the need to prohibit extreme forms of experimentation, such as cloning or the modification of the genome of germinal cells.

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 271–289.

At an international level, also noteworthy are the *Resolution* of the European Parliament in March of 1997, of 7 September 2000 (B5-0710/2000), and the subsequent initiatives of the European Council. They both agreed that human cloning should be categorically condemned. We will return to this point later.

Currently however, the debate has taken a different direction. Contrary to the ontological approach, which is rooted in the notion of human dignity, other lines of argument have recently proliferated. This change of position can be seen clearly in certain sectors of the scientific community that are in favour of allowing human cloning. For example, a statement, signed by 67 Nobel Prize winners was published in an issue of *Science Magazine* (March 1999), in favour of financing research on human embryos with public funds in the United States. Although the arguments at play may be different, it can be seen, with the perspective that time allows, that the transformation of social and scientific opinion is following the same path as that generated by other techniques such as in vitro fertilisation, or the freezing of embryos. At the onset of the debate, a feeling of confusion and alarm is spread (Elmer-Dewitt 1993). Later, the technique in question is said to be justified in some cases. Finally, it is accepted, providing there is a minimum of control, be it merely formal.

Returning to the topic of the techniques of cloning applied to human beings, we can point out that the current debate concerning the moral question of cloning is based fundamentally on four types of argument (Kass 1997):

a) The "technological" perspective, begins with the assumption that cloning, understood as a mere technique, is something neutral, morally speaking. Thus, it lacks intrinsic characteristics of good or bad. The moral classification will depend, exclusively, on the ends or objectives that motivate it. It deals with a consequential perspective that determines the acceptability of experimentation on human embryos by the purpose that motivates the experiment, or the subsequent consequences. Viewed from this perspective, it is not the question whether human cloning is respectful to human dignity or not. Basically, its utility for the rest of the population is under consideration. In this way, one would have to measure its usefulness by means of a kind of cost/benefit analysis. A consequence of this new perspective is the present distinction between "therapeutic cloning" and "reproductive cloning."

b) The liberal standpoint includes cloning in the realm of rights derived from personal self-determination. It deals with the option, among others, included in a generic right to reproduce. At the same time, cloning would go in depth into liberty facing nature itself: women would no longer need the co-operation of a male for reproduction. The male, for his part, would be able to have a child whose genetic characteristics had been inherited exclusively from him. The only moral restrictions would be those of fully informed consent and the prevention of bodily damage to the new human being.

c) From a eugenic view point, cloning carries clear hopes of "improving" human beings. It is argued that in some way, it could contribute to the perpetuation of healthy individuals, progressively eliminating genetic defects. If cloning techniques are linked to those of genetic engineering in a strict sense, one can achieve positive eugenics. Cloning could be justified by the excellence of its ends.

d) Finally, cloning is debated from the premise that it is necessary to recognise human dignity. From this point of view, cloning would assume, basically, the use of the human being as a tool, which would not be acceptable. We will return to this subject later.

It has been pointed out that one of the consequences of the new position is the current distinction between "therapeutic cloning" and "reproductive cloning." The first standpoint would basically pursue the creation of reserves of organs and tissues suitable for transplants (Allmers 1997, 1401). The second would place cloning with the traditional techniques of assisted reproduction.

While science and ethics largely reject cloning for reproductive ends, opinion is not the same when dealing with cloning for the purpose of obtaining tissues or organs for use in transplantation. As previously mentioned, it is admitted that the final purpose is the fundamental element in weighing the acceptability of the action. From this perspective one runs the risk of forgetting that, when the object of experimentation is itself a human being, the ethical evaluation affects the action itself. In this chapter we will analyse the outlined questions, attempting to respond to the arguments arising. In whatever form, we consider that the treatment of this problem must begin with a brief look at the basic scientific aspects of the topic.

SCIENTIFIC ASPECTS OF CLONING

Cloning means the asexual reproduction of organisms or of genetically identical cellular lines. In this study, we refer exclusively to the cloning of organisms. This process can be carried out in two ways: by cellular division and by the transference of nuclei.

Cloning by Cellular Division This technique of cellular division consists of the parting of embryos (bisection) or the separation of blastomeres in the first stages of embryonic development. It has been used in experimental form on laboratory animals. This method consists of separating the embryonic cells and having them develop independently from one another, in order to produce identical embryos (Gindoff 1998). This technique is similar to the mechanism that, in nature, leads to the formation of monozygotic twins (Lacadena 1997, 289).[8] *Cloning by Transference of Nuclei This second technique is based upon the transference, or transplantation, of nuclei to ovules or zygotes from which, at the same time, the "enucleated" nucleus was extracted (Griffin 1998). The transferred nuclei can come from two sources: (1) from undifferentiated embryonic cells; (2) from differentiated somatic cells.* The experiments with cloning by transference of nuclei from embryonic cells began in the 1950s on amphibians. Through this technique, Briggs and King observed that by transplanting the nuclei of blastulae, the development completed normally; while upon utilising nuclei proceeding from more advanced states, their capacity for normal new development was progressively diminished. In 1952, identical spiders were produced through the introduction, into ovules, of cellular nuclei proceeding from the intestine of embryonic tadpoles (1952).[9] From this, it was deduced that differentiated cells were not totipotent. However, later on

Gurdon and Kobel refuted the previous conclusion by obtaining clones started from differentiated tadpole cells.

The cloning of amphibians stimulated the next step: nuclear transplants in mice, cattle, and sheep. Normal animals were obtained in mammals starting from nuclei proceeding from embryonic cells or from their corresponding cultured primary cells. Willadsen achieved the normal development of rams starting from embryos of 8 or 16 cells fused with the enucleated half of a sheep in metaphase II, demonstrating that the nuclei of the blastomeres were totipotent (1986; 1989).

Concerning cloning by transference of somatic cells, it has already been pointed out that the George Washington University announced years ago that, it had managed, in the laboratory, to produce from a human embryo, more embryos with the same genome, using this technique. We know a new milestone in the unstoppable path of cloning was produced in the year 1997: the team at the Roslin Institute obtained viable sheep by reconstructing embryos starting from cultured cells proceeding from the embryonic disks of nine-day-old blastocysts,[11] from 26-day-old foetuses, and from the epithelia of a mammary gland of a six-year-old adult sheep in the last trimester of gestation. In this way, the first cloned mammal was created, from a differentiated cell.

It is interesting to note that the creation of clones by nuclei transfer from somatic differentiated cells is of greater scientific interest than clones resulting from the transfer of nuclei from embryonic cells. A great part of the importance of utilising adult individuals as donors comes, as far as their possible application in mammals is concerned, from their "genetically proven value" (Lacadena 1997, 277). However, it is important to note that, in the case of obtaining clones through the technique of transfer or transplantation of nuclei from diploids to lambs, ovules or enucleated zygotes, one must keep in mind that, although the greater part of cellular DNA is found in the interior of the nucleus of the cell, stored in the form of the chromosomes, there is also another portion in the mitochondria, the cellular structures situated in the cytoplasm.[11] The role of this fragment of DNA has raised a large number of questions that must be answered in future investigations.[12]

In the development of the techniques of animal cloning a new chapter has been opened with the development of embryos from the fusion of cow ovules with cells of primates, rats, pigs, and sheep. Following the technique developed at the Roslin Institute, Neal First, the first researcher to clone mammals using undifferentiated cells from bovine embryos, proved that the transfer of genetic material from different mammals to cow ovules was successfully carried out in every case, despite proceeding from very different species. However, when the zygotes were implanted in the females of the appropriate species for their future growth, the gestations did not complete successfully, possibly due to remaining genetic material that was not conveniently eliminated from the cow ovules.[13]

Cloning experiments received considerable impetus when, in November 1998, it was publicly announced that two American research centres – the University of Wisconsin, with professor James Thomson at the forefront, and John Hopkins University with a project directed by Professor John Geaghart – obtained stem cells – or totipotent cells – starting from initial embryos. This involves with undifferentiated cells, from which it is possible to produce almost all human tissues. The proposed objective was to cultivate cells and to use them afterwards to originate tissues suitable for transplants and the treatment of illnesses in humans. This discovery has generated a scientific and ethical debate. At the heart of the problem is the clear use of human life, the embryo in the service of ends far removed from its own health or wellbeing.

Also along these lines, the American company, Advanced Cell Technology, has announced that it has managed to develop hybrid cells with genetic material from humans and cows. The technique consisted of introducing DNA from the nuclei of human somatic cells into previously enucleated cow ovules. The fusion of both elements was accomplished with an electrical discharge. The company alleges, in defence of these techniques, that its objective is the production of organs for transplants to avoid problems of rejection.

It should, however be taken into account that the use of embryos is not the only way to obtain stem cells. In 1999 the Italian researcher, Angelo Vescovi, published in Science magazine (Vescovi 1999), an experiment that completely turned the debate over cloning and the use of embryonic stem cells around. Vescovi and his team – comprised of scientists from the National Neurological Institute of Milan and the company NeuroSpheres Ltd, from Calgary (Canada) – proved that the stem cells from the brain of an adult rat were able to change identity and to create other tissues. The experiment thus demonstrated that it is not necessary to start from an embryo to obtain pluripotent cells that are capable of generating different tissues. Various centres of investigation have confirmed these results. Thus, for example, in February 2002, scientists from the University of Navarre (Spain) succeeded in obtaining stem cells from adult organisms. Specifically, they managed to repair a heart damaged by heart attack, using stem cells from the patient himself.

ETHICAL PRINCIPLES: IS UNIVERSALITY POSSIBLE?

We have previously indicated that, from the “technological” perspective, it is understood that the objective behind experimentation in cloning is the decisive factor in its ethical evaluation. Nevertheless, it is important not to lose sight of the fact that, as much in the case of cloning for reproductive ends, as in the case of cloning for the purpose of obtaining tissues and organs for transplantation, the object of experimentation is a living being whose genome identifies it, unavoidably, as a member of the human species.[14] From this perspective, the treatment that it may receive cannot be comparable with the treatment of, for example, a tissue or organ alone. Nor can it even be understood to be correct, from an ethical perspective, to treat it like the rest of living beings. This is due to the special dignity the embryo possesses, in an inherent way, as a full member of the human species. Such dignity can be understood as the ultimate foundation of human rights (Spaemann 1988; 1989; Aparisi 1997, 55). In this sense, it is suitably fitting that the *Universal Declaration on the Human Genome and Human Rights*, approved by the 29th Conference of UNESCO on November 11, 1997, begins with the chapter entitled, “Human dignity and the human genome”.

It is common to appeal to the axiom or principle of human dignity, understanding it as the ultimate foundation of moral and legal order[15] and, as a consequence, of the same notion of human rights. However, on many occasions the basis of this concept is accompanied by a patent inaccuracy. The paradox results, partly, because, on the one hand, the appeal to dignity appears as the last and most important link of the argument. To point out that something is contrary to human dignity is presented as irrefutable. On the other hand, the meaning that is attributed to this notion is so ambiguous and variable that, on occasions, it is converted into an expression empty of content.

This current indiscriminate and unfounded use of the notion of dignity does not impede, in our opinion, the re-adoption of this concept to try to illustrate that, in its original content; it displays a virtue in relation to the problems that worry us. The classical idea of ontological dignity can and must be an axial and fundamental principle, since it allows for the extraction of clear demands in this realm (Aparisi 1997, 55).

We start with the understanding that the traditional principle of the dignity of a person means that every human being possesses an excellence or ontological eminence, superiority in relation to the rest of creation. In this way, dignity implies something absolute and not merely relative, since the difference from other beings is not quantitative, but rather qualitative.[16]

Certainly, with the concept of dignity we wish to mean, *grosso modo* the idea of unconditional or absolute respect that is owed to the human being, dealing with something "sacred," outside the realm of commerce (Spaemann 1989, 94; González 1996, 45).[17] Kant already understood that people "are not mere subjective ends, whose existence, as an effect of our action, has a value for us, but rather are objective ends, that is, things whose existence is in itself an end, an end such that in its place no other end can be placed which should serve as a means" (1992, 64).[18]

In short, the dignity of man is that of a transcendentally free being, open to reality by intelligence and will. It deals with an ontological, radical dignity, since it is supported by the nature of the human being. For this reason, dignity is inseparable from the category *Homo sapiens,* independent of certain characteristics belonging to members of the species, which are manifested externally. On the other hand, we have already made reference to the fact that it does not deal with a human right, but rather lays the foundation itself for human rights. Such rights would not be derived from the legal attribution of personality, conceived, in its moment, by the possession of rationality and the capacity for moral self-determination, but rather by dignity. In this sense, Spaemann points out that human rights "must be recognised for every being that descends from man and starting from the first moment of its natural existence, without the requirement of any additional criteria" (1989, 50).[19] For this author,

> if the pretension of belonging to human society were to remain at the judgement of the majority, we would have to define in virtue of what properties human dignity possesses, and the corresponding rights that could be demanded. But this would absolutely suppress the idea of human rights itself. These assume that every man, as a member of society, values his rights relating others, which means in its turn that belonging to the human species *homo sapiens* can only be based upon that minimum dignity that we have called human dignity (1988, 25).

It is important to insist that dignity lies within the being and, due to this, is found in connection with the notion of human nature and the most intrinsic part of it, its end.[20] In this way, one can maintain that every human being, possessor of a radical dignity, is called to behave in agreement with the demands derived from this dignity, linked to the ends of its own rational nature. Dignity does not imply autonomous rights and obligations, but instead that the human being is bound by a set of rules inherent in its own being.[21]

This concept of dignity does not imply a vision of the human being subjected in his behaviour to an external control outside of himself. In this sense Finnis points out that the basic forms of good, understood from a practical level, are what is good for human beings with the nature they possess (1980, 34).

In our opinion, from the ontological view of dignity it is possible to identify, among others, the following consequences in relation to the theme we are dealing with:

1. It concerns a condition belonging, and inherent to, every human being for whom there are no grades or hierarchies. As a consequence, every member of the category *Homo sapiens* must be recognised in the same way, independent of his state of development or physical and mental characteristics.
2. The rights derived from this dignity, being inherent to his being, are limited and influenced by his own being; by his nature.[22] There is behaviour conformant (worthy) and non-conformant (unworthy) with this state. It justifies the existence not only of rights, but also of natural obligations.
3. From an ontological perspective of dignity, the first fundamental right of every human being is the right to life, since its harm implies a radical negation of the very dignity inherent in the being. While the infringement of any right assumes a threat to dignity, the elimination of a human life implies the total eradication of someone whose value is immeasurable. Due to this, every threat to human life results, necessarily, in the very destruction of dignity. Moreover, it should be kept in mind that life is the basis for human rights. In consequence, the right to life must always be elevated above any discourse concerning different types of goods or rights. The death of a human being is never justifiable.
4. This vision allows, in our opinion, the foundation of a universalistic concept of human rights.

CLONING AND THE PRINCIPLE OF AUTONOMY: THE RIGHT TO FREEDOM OF RESEARCH

We consider it important to include in this paper a brief reference to the right to freedom of research, for two reasons:

a) The ethical and legal problems that human cloning poses are, in reality, a consequence of the development of the fundamental right to research and to scientific and technical production. From this perspective, the reference to ethical and legal problems of human cloning refers to the limitation of such a fundamental right.

b) Currently, there is no shortage of those who consider that the prevalent interest must be, in every case, the freedom of research. Such people advocate that the advance of science should justify, in every case, the methods utilised.

It is clear that the human right to research, and to scientific and technical investigation, is a direct consequence of the recognition of human dignity and holds great importance, and should not be underestimated. However, this does not mean that, it may be converted into a source of encroachment on other human rights.

There is no doubt that scientists over the centuries have enjoyed a high level of autonomy. External controls have scarcely been imposed on their activities. Nevertheless, at least in the field of intervention on the human genome, it appears that this principal of absolute freedom and independence is now unsustainable. This right is not absolute, but possesses limits. There are other rights, derived from human dignity, that not only can, but also must limit the freedom of research in certain cases. This does not mean, in any circumstances, the denial of the right, but a consideration of the interests at play, to verify the existence, in some cases, of a conflict of rights, and the need of a hierarchy. This will justify the limitation of this freedom in relation to some scientifically possible options arising from the advances of biotechnology. We can remember the affirmation of the *Declaration of Helsinki*, in the sense that the interest of science or of society must not prevail over the interest of the particular individual.

This position appears generically reflected in the Spanish Constitution. Article 20, section 1b, under the heading "*Of Fundamental Rights and Public Freedoms*," recognises the right to artistic, scientific, and technical production and creation. But the same Article 20, in section 4, emphasises that "These freedoms have their limit in the respect for the rights recognized in the above title, in the precepts of the laws that develop them and, especially, in the right to honour, the intimacy of the very image and the protection of youth and childhood."

In particular, this point is made in the *Universal Declaration on the Genome and Human Rights* from UNESCO quoted above. In its Article 6, it establishes that "No scientific advancement, in the area of biology or genetics, can prevail over the dignity and the rights of the human person". Article 15 provides that

> States should take appropriate steps to provide the framework for the free exercise of Research on the human genome with due regard for the principles set out in this Declaration, in order to safeguard respect for human rights, fundamental freedoms and human dignity and to protect public health...

Moreover, it is important to have in mind that, in the specific field of genetic research, the limits between what is understood as basic research and its applications have become imprecise. In this sense, Jonas points out that the experiment, unlike its previous delimited role in research, is involved with the original production of the object being experimented on, converting the process of knowledge into an originating action (1977, 73). In the case of human genetic research, what exists between the beginning and the end of the experiment is the real life of members of the human species. This eliminates all separation between research and application. According to Jonas, "the experiment is the true fact...and the true fact, the experiment" (1977, 112).

On the other hand, it should be kept in mind that when research is done on living organisms, and especially on members of the human species, that even when the end being pursued is legitimate, the means employed can convert such an activity into an unjust one, morally speaking. This happens, very clearly in the assumptions surrounding the cloning of human beings. We have already pointed out that, in this case, the freedom of research must be contrasted with some legal rights and goods at stake. Concretely, it becomes necessary to recognise and guarantee, fundamentally, the right to life, health, integrity, and genetic individuality of every human being. We will return to this later.

THE ETHICAL EVALUATION OF THE CLONING OF HUMAN EMBRYOS

At the beginning of this chapter we made reference to the actual distinction between cloning for reproductive purposes and cloning directed at obtaining tissues and organs suitable for transplantation. Frequently, from a consequential standpoint the ethical evaluation of each one of these techniques is different. For example, in the Congress organised by UNESCO, in May 1997, under the title “Animal Biotechnology, Cloning, and Transgenic Technology,” a great number of participants emphasised the distinction between reproductive cloning of human beings destined towards the birth of an individual, and the non-reproductive techniques of cloning of human beings for the purposes of research. For some, the latter technique deserves a different ethical qualification.

This reductive attention to the consequences that are derived from the technique for its ethical evaluation has meant that, on occasion, a certain piece of information can be lost from view: both modalities imply the fulfilment of a basic action, the creation of human embryos with the same genome as another human being. The only difference is the end purpose that motivates the experiment. Nevertheless, it is a traditional principle in ethics for actions never to be evaluated exclusively by their personal or social consequences or, in more colloquial terms, the end does not justify the means.

One must keep in mind that both types of cloning have another common characteristic: the motive that determines the application of the technique is never for the benefit or wellbeing of the cloned individual. Unlike what occurs in relation to another type of technique, for example germinal genetic therapy, the cloning of human embryos does not pursue the health or wellbeing of this individual. On the contrary, its creation is presented, in any case, as a mechanism for satisfying an interest that is never it’s own, but rather, outside it. That brings us to maintain that the cloning of human embryos always uses members of the human species as a tool, which is a direct contradiction to the idea of human dignity.

Another of the demands derived from the notion of human dignity is the necessary respect for the uniqueness and individuality of every human being. From this perspective it is clear that every cloning of an embryo assumes a threat against such biological uniqueness of the human subject. Likewise, it is important not to forget that the application of the techniques of human cloning can lead to, in many cases, an exacerbation of the eugenic mentality. Finally, it is important to keep in mind the unsafe nature of these techniques at the moment. This lack of safety is so high that it becomes, in itself, another ethical argument to be used against them.

The Use of The Human Being As A Tool As discussed earlier, cloning converts members of the human species into objects in the service of ends that are foreign to them. It implies the use of the embryo as a tool, as it is no longer considered, to utilise the Kantian expression, an "end" in and of itself, but instead receives the legal status of "thing" or object. Allowing the cloning of human embryos can bring about the commercialisation of the human body, and its organs and tissues. The European Advisory Group on the Ethical Implications of Biotechnology (GECIEB) has declared itself against human cloning and the use of a person as a tool. Its president, Noëlle Lenoir, has declared that this use of the human as a tool begins the moment that the technique of human cloning of a person is used to satisfy a need of personal or utilitarian nature (1998).

Now, it does not seem coherent to prohibit this technique on the basis of a possible utilisation of the human being as a tool, and to not show any objection to the techniques of *in vitro* fertilisation. If there exists any risk of making an object of the human being, by creating it exclusively to satisfy a determined need or want, like that of having descendants, the same risk exists in the creation of a "test-tube baby." This risk of considering the new being as a means, and not as an end in and of itself, is also seen to be increasing, for example with the choice of sex through *in vitro* fertilisation.

A Threat to the Biological Uniqueness of the Human Subject Among the reasons against the application of the techniques of human cloning we have outlined the threat against the biological uniqueness of the human subject. The respect for such uniqueness is derived directly from the recognition of the dignity of the individual. Lacadena states that "the characteristic of uniqueness (being unique or not reproducible) together with that of unity (to be one) are fundamental in the process of the individualisation of the human being" (1997, 291). For this reason, "the obtaining of cloned individuals would be a threat against human dignity and, therefore, it would be ethically unacceptable." There has been discussion recently, of the need to recognise the existence of a new human right, closely related to the right to free expression of personality: the right to genetic individuality. This deals with the right to uniqueness and the right of every individual to possess their own original genetic code and to express it without interferences that might endanger its integrity or diminish its originality. Each member of the human species must be the result of a unique and impossible to reproduce, recombination of two genomes. The subject of this right would be, therefore, the new human individual generated in the moment of fusion between the ovule and the spermatozoid.

Definitively, this new right would guarantee that every human being is unique and impossible to reproduce being, due to their genetic make-up that could carry out its life project without being programmed by external expectations, desires, or interests Cloning ignores the individualised and dignified value of being marvellously different from the rest. From our point of view, the unforeseen is preferred over whatever ideal or stereotype of a person is imposed or proposed by an outside will. The value of each member of the human species is found totally and radically in their own being, not in their external characteristics. The Parliamentary Assembly of the European Council in 1982 has already referred specifically to the right of genetic integrity in its Recommendation 934.

The response to this is the allegation that cloning would never achieve exact identical individuals. In this sense it is maintained that from the possibility of obtaining a replica of the bodily structure, a perfect identity would not necessarily result, understood as much in their ontological as in their psychological reality. This argument is reinforced by scientific data, previously summarised, relating to the existence of mitochondria genes.

It would be fitting to respond to this argument by stating that the human being is a "unified totality. The psychic dimension as much as the physical, belong to its most profound being" (Aparisi 1997). Thus, a part of its integrity is its genotype. Its manipulation assumes an unjustified interference. By allowing this, one would arrive at a new kind of slavery in which an important part of the totality of a human being would depend upon a will outside of itself.

On the other hand, one must keep in mind that the concept of genetic patrimony has not only an individual or particular dimension, but also a public one. We cannot forget the connection between the genetic structure of a human being and future generations. Also, we must emphasise the value that genetic diversity holds, key to the survival of the human species. The respect for human dignity also means a collective responsibility regarding the human genome.

Eugenics To the general arguments already used against the ethical and legal admissibility of human cloning, that of eugenic ideology must be added.[23] *Cloning, being able to obtain genes considered "favourable" to appear more frequently in the human population, would encourage considerably the social expansion of such an ideology.* Before carrying out any type of ethical evaluation, it is important to clearly distinguish two assumptions:

1. The intentions, ethically laudable, to eradicate illnesses. The fight against human illnesses cannot be considered, in its own sense, a kind of eugenics.

2. The stated eugenics ideology itself. In this case we do not find ourselves before a mere intention of combating human illnesses. On the contrary, the eugenics ideology starts with some concrete anthropological assumptions: the intrinsic value of a human will depend, fundamentally, on its genetic characteristics. In its most radical manifestation, eugenics defends either the sterilisation of carriers of defective genes, or the elimination of the gene. In either case, the rejection of pathology or of the "defective gene" extends itself to that of the carrier himself. Based on these assumptions, it is clear that eugenic ideology implies a radical anthropological reductionism, and at the same time, is loaded with discrimination and is harmful to human dignity.

Safety It is important to insist that the lack of safety in these techniques become one more ethical objection. In this sense, one must keep in mind the cloning done on mammals: In order to clone an animal a great number of embryos have had to be used, producing deformities and the death of many of them (Aparisi 1999).[24] On the other hand, these practices can place the equilibrium founded on biological diversity in crisis and possibly provoke unintentional, but extremely dangerous consequences for future generations. In this way, Harry Griffin, Adjunct Director of the Roslin Institute, has expressed that it is not known if Dolly has a legacy hidden in her genes, although her external appearance may be good. The premature death of Dolly undoubtedly appears as further proof of the unsafe nature of the technique. On the subject of the possible problem of mutations, Griffin responds that "it requires the use of rats, and three decades of reproduction would be needed to get conclusions" (Bravo 1998, 37). All things considered, although clear proof may not exist concerning the risks of the cloning of mammals, doubt alone must impose the moral obligation on the researcher of extreme caution and of the need to control such techniques.

We have previously pointed out that one of the consequences of the new views on human cloning is the actual distinction, regarding the objectives pursued by the technique, between reproductive cloning and cloning for ends other than human reproduction – fundamentally obtaining tissues or organs suitable for transplantation. Up until now, we have presented a general treatment of the subject, supporting some reasons that determine its ethical and legal unacceptability. In the pages that follow, we will make a brief reference to the characteristics and problems specific to each one of these types of cloning.

HUMAN REPRODUCTIVE CLONING: THE RIGHT TO INTEGRITY AND GENETIC INDIVIDUALITY

As we have already seen, from a liberal perspective, human cloning could be situated in the realm of rights derived from personal self-determination. It would deal with one more option included in a generic right to reproduce. From this perspective, the technique termed "reproductive cloning" would allow one to achieve, among others, the following objectives:

a) The replication of individuals of great genius or beauty.

b) Reproduction of a loved one, dead or alive. .

c) Having children within a sterile couple.

d) Finally, the possibility of using the technique with the objective of getting healthy individuals has also been posed. It is maintained that it would be an option for those couples with a serious risk of transmitting genetic diseases.

All of these assumptions must be analysed from a clear perspective: the rights of the new being generated from these techniques of cloning. In either case, the recognition of the aforementioned right to integrity and genetic individuality would be at stake. From this perspective it would be fitting to admit that individual self-determination has as a clear limit the rights of another, a new being.

CLONING WITH ENDS OTHER THAN HUMAN REPRODUCTION

Among the objectives pursued by this kind of cloning would be:

1. The creation of reserves of organs and tissues for transplants (Allmers 1997, 1401). As we have already pointed out, the rise of so-called "therapeutic cloning" is linked to the recent success in obtaining cultured stem or totipotent cells. Combining the techniques of cloning by nuclei transfer with this discovery, it is possible, in the opinion of some scientists, to get undifferentiated cells whose genetic material is

identical to that of a particular donor. From this perspective, it has been pointed out that the cloning techniques for human embryos would open up opportunities in the field of biomedicine.

2. The opportunity to study cellular differentiation, of great importance for transplants.

3. Obtaining genetically identical results to carry out scientific studies. It is clear that, for a clinical experiment to be carried out, it would be of great help to have the most homogeneous population possible, comparable to how animal research is conducted.

It is important to start from the idea that these types of cloning imply the destruction of a cloned embryo. For this reason, they are contrary to the idea of dignity, harmful to the right to life. We base our position from this point onwards, on what has already been established regarding the use of the human being as a tool.

HUMAN CLONING AND THE LAW

Experience shows that legislation is very slow in reacting to scientific and technological advancements (Aparisi 1997). Ethical and legal reflection usually appears when the negative effects have already been produced.[25] However, in the debate over cloning; the trend has been somewhat different. If the necessary ethical and philosophical reflection on the topic has been lacking, the legal reaction has been unsuitably rapid. As previously pointed out, various provisions have been made both at the level of international organisations and at the level of the internal law of various countries.

Already in the year 1989, the European Parliament approved a *Resolution on the Legal and Ethical Problems of Genetic Manipulation* (O.J. C 96, 17/04/1989). In point 41 it maintains:

> Consider that prohibition under sanction is the only viable reaction to the possibility of producing human beings through cloning, as well as with respect to all those experiments which have as their end the cloning of human beings.

However, the most severe legal reaction was a result of making known, publicly, the experiment that led to the creation of the sheep Dolly. Only one month later, on March 12, 1997, the European Parliament approved a Resolution on cloning (O.J. C 115, 14.4/92, 12/03/1997). It flatly states that

> cloning of human beings, whether experimentally, in the context of fertility treatment, preimplantation diagnosis, tissue transplantation or for any other purpose whatsoever, cannot under any circumstances be justified or tolerated by any society, because it is a serious violation of fundamental human rights and is contrary to the principle of equality of human beings as it permits a eugenic and racist selection of the human race, it offends against human dignity and it requires experimentation on humans.

The Resolution calls for the adoption, at an international level, of ethical norms concerning biotechnology and for the financial restriction of experiments on cloning of human beings. Also, it highlights that the direct guardianship of the right of individuals is above any social interest or third party.

In April 1997, representatives from 20 countries signed the *Convention on Bioethics*, elaborated by the Council of Europe. The importance of this document lies in the fact that it is the first one created as binding by the International Community. In its Article 1 it maintains that the signing parties from the Convention will protect the dignity and identity of all human beings. On its part, Article 2 defends the primacy of the human being over the interests of society or science. Likewise, Article 18.2 opposes the creation of human embryos for research.

To this *Convention,* an additional Protocol on Cloning has been added. This maintains, in its Article 1, that: "Any intervention whose end is the creation of human beings genetically identical to other humans, alive or dead, must be prohibited."

For its part, the *Universal Declaration on the Human Genome and Human Rights* by UNESCO, maintains in its Article 2 that: "(1) Every individual has the right to the respect of his dignity and rights, whatever characteristics he may possess; and, (2) This dignity demands that individuals not be reduced to their genetic characteristics, and that the unique character and diversity of every person be respected." And in its Article 11 it maintains that:

> Practices contrary to human dignity, like cloning for human reproductive purposes, must not be allowed. One invites the nation states and competent international organizations to cooperate in identifying these practices and to adopt on a national and international scale, the corresponding measures, to assure themselves that the principles set out in the present Declaration are respected.

The Catholic Church also has spoken out on different occasions on this subject. A note published in the journal of the Holy See, *L'Osservatore Romano*, under the title "An Imperious Demand on Reason and Humanity," encouraged nation states to not make concessions when facing pressure from possible trends disposed to support human experimentation utilising the techniques applied to animal reproductive cloning. For its part, the Pontifical Academy for Life has declared that stopping the human cloning project is a moral compromise that must also be translated in cultural, social, and legislative terms.

Likewise, many nations have incorporated into their legal systems precepts that prohibit human cloning. It is important to point out that, before 1997 the *Law for the Protection of Embryos*, of December 13, 1990 already prohibited cloning in Germany.

The most powerful reaction can be found in Italy whose Ministry of Health prohibited these experiments even on animals. In the United States, experimentation on embryos, although legal, is subject to a financial veto. In this way it is prohibited to publicly subsidise those experiments that allow or facilitate human cloning, as it is considered morally unacceptable. Due to the lack of specific legislation on cloning in the United States, the Food and Drug Administration (FDA) assumed the responsibility of regulating the application of these techniques. The FDA maintains that human cloning is a form of genetic therapy and, therefore, is subject to prior permission from federal authorities.

In Spain, the law that regulates the *Assisted Human Reproduction Techniques* made it an offence subject to sanction, as a very serious administrative infraction, "to create identical beings by cloning or other procedures directed at the selection of race."[26] Subsequently, the Criminal Code of 1995 elevated the conduct previously considered as a very serious administrative infringement to a criminal category.[27]

Article 161.2 penalises "the creation of identical human beings by cloning or other procedures directed at the selection of race." Penal intervention must be understood as the last resource in order to avoid the damage to legal goods, not as an obstacle to scientific research. In the case of cloning, would be expressed precisely in the right not to be reproduced, identity, individuality, and the very authenticity of the human being.

Just as in other countries, the punishment set down by the Spanish Penal Code is insufficient, since it is reduced to 1–5 years of prison with special disqualification for employment or public position, profession, or office for 6–10 years. In accordance with our penal system, prison could be avoided in a case with no previous convictions.

Finally, it is important to point out that in the legal sphere there is a new approach relating to the theme at hand, to carry out the legal and ethical evaluation of ends or objectives that motivate a cloning experiment. This position clearly appears in the United Kingdom. The study made in January 1998 by the *Human Genetics Advisory Commission and teh Embryology and Fertilization Authority* confirms the favourable position of the prohibition of human cloning for reproductive purposes, but not the cloning of human embryos for therapeutic or scientific purposes. Subsequently, the reform of English Law relating to fertilisation and human embryology, in 1990, opened the way for research into human cloning for scientific purposes. Faced with this situation, the European Parliament of September 2000, made the following declarations:

> "Considering that human dignity and the consequent value of the human being are the main objectives of the member states as proclaimed in many modern Constitutions (…) Considering that there are methods of curing serious illness without resorting to cloning embryos, such as methods which involve obtaining mother cells from adults or the umbilical cord of recently born babies (…) Considering that we find ourselves up against a new semantic strategy that attempts to weaken the moral significance of human cloning (…) Considering that there is no difference between cloning for therapeutic purposes and cloning for reproductive purposes and that any relaxing of the current prohibition in force, will give rise to pressure for the continued development of the production and use of embryos (…) It considers that human rights and the respect for human dignity and human life must be the constant objective of political legislative activity (…) It considers that therapeutic cloning that involves the creation of human embryos for the purposes of research, raises a profound moral dilemma, entailing crossing irreversibly the limits of the rules of investigation and is contrary to public policy approved by the European Union (…) It reiterates the appeal to all member States to proclaim legally binding regulations that prohibit research into any type of cloning of human beings in their territory, and the setting up of penalties for all violation of such regulations (…) It asks for the greatest effort possible at a political, legislative, scientific and economic level, to encourage techniques that use stem cells obtained from adults (…)."

In conclusion, we wish to point out that, in this field, prohibition or moratorium are not intended to delay or overshadow, but rather to value the possible injury to human dignity, as well as examine the side effects or repercussions that accompany the technique. Hope in science cannot be disappointed. Nonetheless, one must start from the assumption that advancement at any cost is not permitted. The irrevocable limit is respect for the dignity of every individually considered human subject. The problems referred to highlight the fact that, currently, man finds himself, more than ever, facing important choices that, will decisively determine the future of the human species. It can be maintained that the destiny of humanity will largely be determined by the answer to the question of whether the human embryo is a thing, a human being, or intermediate entity yet to be defined. What we are debating, in summary, is the notion of the human being itself and the meaning of dignity. Respect for dignity means that, in the scientific world, not everything that can be done, should be done.

NOTES

[1] Nevertheless, the beginning of enucleation of ova to serve as an incubator for a cell was proposed, in 1938, by the German embryologist Hans Speaman (Postel-Vinay and Millet 1997, 536).

[2] The result of the famous project, carried out by Wilmut, Schnieke, et al. (1997) was published in the magazine *Nature* with the title of ""Viable Offspring Derived from Foetal and Adult Mammalian Cells". Until that date, due to chromosomal anomalies that induced the suspension of development, the failures with mammals had been quite high. Wilmut and his team introduced the new development of the suspension of the cycle of donor cells. This aspect could be considered decisive, although it is still premature to conduct an evaluation.

[3] However, it is important to keep in mind that publications referring to cloning by the transfer of nuclei have existed since the 1970s. For that reason, the concern generated in the scientific world by the creation of the sheep Dolly, seems rather exaggerated. (Winston 1997).

[4] Schettles (1976) achieved clones of human beings by obtaining zygotes that multiplied themselves until they produced embryos. The procedure consisted of taking the nucleus of the cell of a male, eliminating the nucleus of the ovule, and inserting the nucleus of the somatic cell in the germinal. It was proved that the manipulated ovule behaved just like one fertilised by a spermatozoid.

[5] It is important to point out however, that the cloning of animals is not lacking in ethical relevance. At the start, it is important to distinguish that the techniques used for animal cloning can have some positive consequences for human beings. The OMS has made the point that such techniques widen the possibility for making progress in the biomedical research on the diagnosis and treatment of illnesses that affect man. To rely on genetically identical organisms can help elucidate the aetiology of illnesses (Organizzazione Mondiale della Sanitá 1997). On the other hand, it should be made clear that all pharmaceutical companies with research-based activities use genetic engineering as a habitual technique. The cloning of transgenic animals as producers of new therapeutic proteins has generated a great interest in these companies. This gives rise to some ethical problems: first, is whether genetic experimentation on mammals is beyond any limits. We must ask ourselves what human benefit justifies animal cloning. Or what types of goods will make that determination? Does a possible therapeutic or nutritional success justify subjecting animals to techniques and studies that will change them radically, or will expose them to extreme danger? The National Commission on Bioethics of Italy has manifested that the cloning of animals and vegetables (except man) can be accepted if it has a purpose that corresponds with the promotion of human or environmental good, therapeutic in particular, and is not reduced only to commercially lucrative terms; if it does not put animals in danger of unjustified suffering disproportionate to the good to be achieved, and does not assume an implicit attempt or risk for biodiversity (1997, 360–2). It is interesting to distinguish this last requirement because, frequently, the achievement of gain through cloning has been criticised, presenting it as a danger, upon assuming a threat against biodiversity. This affirmation is difficult to maintain at the moment due to the low efficiency that these techniques show. Some authors ascertain that, it will possibly never become a real problem. From their point of view it is not logical that one could arrive at a situation in which all the herds will be clones. There would exist small herds with genetic differences between each other and would result in different objectives being pursued through such techniques. Nevertheless, it would be fitting to ask these questions looking at a not too distant future, when the technique is more developed. Cloning and the fulfilment of genetic characters more profitable quantitatively and qualitatively, could imply, in the long run, a serious threat to biodiversity.

[6] The *Bulletin of Medical Ethics* ((1997) v. 125: 3–5; v. 126: 4–8; v. 127: 7) has published a compilation, in successive numbers, of the legal situation of human cloning in different countries.

[7] Nevertheless, the OMS maintains that the opposition to human cloning must not drive an undifferentiated prohibition to all forms of cloning. The cloning of human cellular lines is used for providing monoclonal antibodies for the diagnosis and study of certain illnesses such as cancer.

[8] The identity of clones is relative. An example of this is seen in nature with monozygotic twins, individuals that are genetically identical, with the same genetic code. However, later on they do not stay the same: there is a series of differences brought about by environmental factors. These include not just the educational factor, but also intrauterine nourishment. They can have the same features and physical characteristics, but they are not completely identical. Even in twins, fingerprints are different.

[9] In 1975, Bromhall achieved the multiplication of rabbit clones. Similar experiments were done by Hoppe, of the *Jackson Laboratory* in Bar Harbor and in the early 1980's by McGrath and Solter (Santos Ruiz 1994).

[10] This technique was already developed by Wilmut in 1996 (Campbell, McWhir, et al. 1996).

[11] The mitochondria are cellular organelle that is present in the cytoplasm of all the cells of the eukaryotes. In human beings every mitochondria contains around ten chromosomes. The mitochondrial chromosome is circular and consists of 16,569 base pairs. The chromosomes in any one given mitochondria are identical, save for possible mutations. The number of mitochondria per cell is quite constant, but varies according to the cell type and function. Currently, 59 genetic disorders of mitochondrial origin are known (Abrisqueta 1995). In this way, the DNA of Dolly has two predecessors: that of the nucleus, which is contributed by the differentiated cell of an adult and that of the mitochondria which proceeds from a recently formed ovule (Spier 1997).

[12] Among other questions, the following could be reviewed: Are the orders for embryonic development in the mitochondrial genes? What types of actions are regulated from the cytoplasm? In any case, it can be said that the cloned individuals obtained by nuclei transfer have a lower degree of identity than the monozygotes, because the cytoplasms are different. On the mitochondrial DNA, one can consult Wallace (1997).

[13] *ABC* Network, 20 January 1998.

[14] In January, 1998, The Institute of Bioethics in the Foundation of Health Sciences, held a Conference on the Science and Ethics of Cloning, in Madrid. Point 5 of their conclusions makes reference to human dignity in the following terms: "The supreme beginning of ethics is and cannot be other than the dignity of each and every human being. This is the criterion that must always direct the judgements on the correctness or incorrectness, kindness or evil of our actions" (Bravo 1998, 36).

[15] The Spanish Constitution, in its Article 10.1, maintains that, "the dignity of the person, the inviolable rights that are inherent to him ... are the foundation of political order and social peace." The German Constitution, in its Article 1 maintains that "The dignity of man is inviolable."

[16] On the other hand, it is important to remember that the possibility of our approaching the concept of dignity will depend closely upon the theory of knowledge from which we start. It is evident that in empirical terms, by reducing all knowledge to sense experience, the idea of dignity when referring to a universal will not be permitted. Universals are ideas, concepts, and enunciated things that our minds create, based on partial information, but it is not for this reason that they are lacking a certain agreement with reality. The universal is a construction of reason, but, at the same time, it is a reflection of reality.

[17] In this sense, for Kant "that which has a price can be substituted by something equivalent; unlike that which is above any price and thus cannot be substituted; this has dignity" (1992, 71).

[18] And in another fragment of Kant's work: "Rational beings are called persons because they distinguish their nature as ends in and of themselves, that is, as something that cannot be used merely as a means, and therefore limits in that sense all capriciousness and is an object of respect" (1992, 64).

[19] González maintains that "this dignity is at stake when anybody assumes the right to decide which beings deserve the name of persons and which ones do not. Because then they easily become considered as a pure means, and they are submitted to utilitarian calculations. The weak, the unproductive, the crippled, children, the sick, could become progressively excluded from the definition of person, and the exclusion could easily justified by needs of the State and as a last resort,

by convenience. In this case, there is nothing more to remember than, that dignity, unlike value, is not measurable" (1996, 54–5).

[20] González points out: "what makes a vegetable, a vegetable, and distinguishes it from man, is an end that the vegetable cannot transcend ... Analogically, what makes animal an animal, and what distinguishes it from man is an end that the animal cannot own. Along the same lines, what makes a human being a human being – his nature – and what distinguishes him from God, is another end that man cannot transcend ... This excludes the possibility of attributing an absolute autonomy to man. Not only in his being, but also in his operating, man has something given: the first principals; these are what define his specific nature" (1996, 97–9).

[21] Such a concept of human dignity is separated, clearly, from the direction of thought inspired by Kant. This last one, as it is well known, understands dignity from a merely empirical mode, lacking normativity. In his *Metafísica de las costumbres*, Kant refers to "the dignity of a rational being as not obeying any other law than that that he makes for himself ... as legislator in the kingdom of ends, free with respect to all natural laws and dignity of human nature and all rational nature" (1992, 92-4). In short, dignity is translated, fundamentally, as the moral autonomy of the conscience.

[22] It does not deal with, therefore, rights derived from the legal attribution of personality, this conceded, in its moment, by the possession of rationality and the capacity of moral self-determination. In this sense, Spaemann indicates that human rights "must be recognized for every being that descends from man and from the first moment of his natural existence, without the requirement of any additional criterion" (1989, 50). For this author, "if the pretension of belonging to the human society were left to the judgment of the majority, we would have to define in virtue of that properties that human dignity possesses and that the corresponding rights can be demanded. But this would be to suppress absolutely the very idea of human rights. These assume that every man, as a member of humanity, can make his rights have value in relation to others, which means in its moment that belonging to the homo sapiens species can be based only on that minimum dignity that we have called human dignity" (1988, 25).

[23] Eugenics is the "study and cultivation of the conditions and means most favourable to the physical and moral improvement of future human generations" (*Diccionario terminológico de Ciencias Médicas*, Barcelona, Salvat, 1974). Actually, eugenic doctrines driving to improve the race and to value the person for his racial and genetic characteristics are not a new development. Therefore, for example, we can remember the great repercussion that the eugenic proposal of Francis Galton (1822-1911) had. The investigative work of this celebrated British anthropologist was seen as clearly influenced by the cultural, social and scientific impact that of the publication "The origin of species," by Charles Darwin. This author not only exposed the transformability of species thanks to mechanisms of natural selection, but also warned against the possibilities of influencing that process by artificial means.

[24] The scientists who created Dolly have admitted that the clones suffer from gigantism and that the animals die young. Ian Wilmut has recognised that "all attempts to eliminate this serious problem have failed, which puts the whole project in danger" (1997). As for human cloning, the team of Wilmut made it clear, before a group of British Members of Parliament, that the application of the technique to humans, if it is quite possible, would be offensive. He clarified himself by saying that if some group were disposed to experiment with a thousand human eggs (the same quantity utilised to clone the sheep), it would be fitting to expect significant progress in one or two years (1997, 717).

[25] In this sense, Hidalgo maintains that it is dangerous to experiment first and reflect afterward. It becomes necessary, therefore, for the "compromise of the international community to sanction norms that regulate these practices (human cloning), in virtue of that it is the future of humanity that is at stake" (1996, 57).

[26] *Ley 35/1988* (Nov. 22nd), modified by *Ley 45/2003* (Nov. 21st). BOE, 24 Nov. (1988).

[27] BOE 24 Nov. (1995).

REFERENCES

Abrisqueta, J.A. (1995) Mapa fisico-patológico de los cromosomas humanos. A*nales de la Real Academia de Farmacia* 61, 309–38.

Allmers, H. (1997) Ethics of cloning. *Lancet* 349, 1401.

-

Aparisi, A. (1997) *El Proyecto Genoma Humano: reflexiones sobre sus relaciones con el Derecho (The Human Genome Project: Reflections on its Relation to Law).* Tirant lo blanch, Valencia.

Aparisi, A. (1999) Genetic Manipulation, Dignity and Human Rights. *Persona y Derecho* 40.

Bravo, I. (1998) La clonación de seres humanos a debate. *Mundo científico* 189, 36.

Briggs, R. and King, T. (1952) Transplantation of living nuclei from bastula cells into enucleated frogs eggs. *Proceedings of the NIH Academy of Science* 38, 455–63.

Campbell, K.H.S., McWhir, J., Ritchie, W.A., Wilmut, I. (1996) Sheep cloned by nuclear transfer from a cultured cell line. *Nature* 380, 64–6.

Elmer-Dewitt, P. (1993) Cloning: Where do we draw the line? Time November 8, 33–38.

Finnis, J. (1980) *Natural Law and Natural Rights*, OUP, Oxford.

Gindoff, P.R. (1998) Clonación por separación embrionaria, *En las Fronteras de la Vida: Ciencia y Ética de la Clonación:* 52–61. Fundación de Ciencias de la Salud, Madrid.

González, A.M. (1996) *Naturaleza y dignidad.* Eunsa, Pamplona.

Griffin, H.D. (1998) Clonación por transferencia de núcleos, *En las Fronteras de la Vida: Ciencia Ética de la Clonación*: 62–76. Fundación de Ciencias de la Salud, Madrid.

Hidalgo, S.N. (1996) Cloning or mass production of human beings, an alternative of the twenty-first century? The law and the human genome magazine, 4, 57.

Jonas, H. (1997) *Técnica, medicina y ética. Sobre la práctica del principio de responsabilidad.* Paidos, Barcelona.

Kant, E (1992) *Fundamentación de la metafísica de las costumbres.* Real Sociedad Económica Matritense de Amigos del País, Madrid.

Kass, L.R. (1997) Clonación: La naturaleza es prescindible. *Cuadernos de Bioética* 3, 1194–5.

Lacadena, J.R. (1997) La clonación: aspectos científicos y éticos. *Anales de la Real Academia de Farmacia* 63, 289.

Lenoir, N. (1998) La clonación y el hombre, *En las Fronteras de la Vida: ciencia y Ética de la Clonación*. Fundación de Ciencias de la Salud, Madrid.

National Commission on Bioethics (1997) La clonazione come problema bioético. *Medicina e Morale* 2, 360–2.

Organizzazione Mondiale della Sanitá (1997) Declaration sur le clonage. *Medicina e Morale* 2, 323–7.

Pennisi, E. (1997) The lamb that roared, *Science* 278, 2038–9.

Postel-Vinay, O., and Millet, A. (1997) Qué tal, Dolly? *Mundo Científico* 180: 536.

Santos Ruiz, A. (1994) Manipulación genética e intervención en embriones, *Manual de Bioética General*, 184–5, Polaine-Lorente, A. (Ed.). Rialp, Madrid.

Schettles, L.B. (1976) Diploid nuclear replacement in mature ova with cleavage. *American Journal of Obstetrics and Gynecology* 133, 22.

Spaemann, R. (1988) Sobre el concepto de dignidad humana, *Persona y Derecho*, XIX.

_____. (1989) *Lo natural y lo racional: ensayos de antropología (The Natural and the Rational: Essays on Anthropology)*, trans. D. Innerarity and J. Olmo, Rialp. Madrid.

Spier, R. (1997) Clones on stage. *Science and Engineering Ethics* 3, 106–8.

Vescovi, A.L. (1999) Turning Brain into Blood: a Hematopoietic Fate Adopted by Living Adult Neural Stem Cells. *Science* 283, 534–537.

Wallace, D.C. (1997) Función normal y patológica del AND mitocondrial (Normal and pathological functioning of mitochondrial DNA). *Investigación y ciencia* 253, 12–20.

Willadsen, S.M. (1986) Nuclear transplantation in sheep embryos. *Nature* 380, 64–6.

_____. (1989) Cloning sheep and cow embryos. *Genome* 31, 956–62.

Williams, N. (1997) Cloning sparks calls for new laws. *Science* 275, 1415.

Wilmut, I., Schnieke, A.E., McWhir, J., Campbell, K.H.S. (1997) Viable offspring derived from foetal and adult mammalian cells. *Nature* 835, 810–3.

Winston, R.M. (1997) The promise of cloning for human medicine, *Bulletin of Medical Journal*, 913.

GEORGE P. SMITH, II

CHAPTER 20

ACCESSING HEALTH CARE RESOURCES: ECONOMIC, MEDICAL, ETHICAL AND SOCIO-LEGAL CHALLENGES

INTRODUCTION AND OVERVIEW

International Law Underpinnings

In 1765, William Blackstone recognized a theory of "absolute rights" – born from the natural liberty of mankind and "founded in reason." (Kunneman, 1995, 339). As a consequence, legal definition and structure were conferred upon those rights which, today, are recognized as human rights (*id.* 339). Within the current human rights debate, as shaped by history, the ethical principle of autonomy or self-determination is seen as the foundation upon which the focus and the very validity of debate continues (*id.* 339). Today, human rights must be seen as rights transcending geo-political boundaries (Goodhart, 2003) and acknowledged as fundamental to life, liberty and the pursuit of happiness for all citizens of the world. Indeed, as David Thomasma observed, "Human rights are grounded in the community and in nature itself" (Thomasma (a), 2001, 307–08).

By way of providing a substantive transnational framework for both validating and codifying human rights, the United Nations, in 1948, adopted The Universal Declaration of Human Rights and thereby sought to universalize human rights (Smith (a), 2000, 8). Although not a binding treaty, the Declaration has fostered and encouraged "a culture of human rights" (Steiner and Alston, 1996). Article 25(1) of the Universal Declaration in fact guarantees adequate health and medical care to all. This action was taken to shore up the rather vague initial acknowledgment in the United Nations Charter of 1945 affirming "that dignity and worth of the human person" (*id.*).

Supplemented, for example, by the International Covenants on Economic, Social and Cultural Rights (Art. 15) as well as the one on Civil and Political Rights that have shaped the customary acceptance of some sixteen groups of human rights (Smith (a), 2000, 10), together with the 1946 World Health Organization Constitution, the European Convention for Protection of Human Rights and Fundamental Freedom, the 1993 Vienna Declaration from the World Conference on Human Rights and the Human Rights Act of 1998 passed by the British Parliament, human rights have been elevated to and equated with fundamental freedoms (Simma, 1991; Paust, 1992).

In order to shape access to health care resources – which would thus advance a claim to an ultimate aspirational goal of a right to health – a workable definition of what precisely a right to health includes must be given. Article 3 of the European

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 291–307.

Convention of Human Rights mandates only equitable access to health care of appropriate quality. Of course, this does not mandate what form of health care is accessible or appropriate (Smith (a), 2000, 15). Indeterminancy, thus, is a serious central weakness to a stabilizing the very right to access health care.

Certainly as important – if, perhaps, not even more important than these international *macro* frameworks for securing human rights in this area – are their *micro* (or individualized) mechanisms. In other words, the vectors of economic force that shape an initial right of access to the health care market system must be studied, evaluated and contained before they are placed within an international context of application (Monagle and Thomasma, 1988).

No definitive structure for normative decision making in health care resource management will be constructed in this Chapter. Indeed, finding what may be considered a "just" solution to the selective distribution of finite health care resources is a task of great, overpowering magnitude and perhaps a "near impossibility." (Mason et al., 2002, 365).

Controlling costs while limiting access to health care resources and constraining choices thereto remains the central dilemma confronting health care policy. (Childress, 1997, 259–262). One over-riding point is clear: namely, so long as restrictive levels of use for health resources exist, some principle of "maximum societal benefit" must be set. Accordingly, the individual's unfettered right to access and equality of use must – to some extent – be compromised in order to safeguard the general need. (Mason et al., 2002, 368).

The health care compromises made, the values and public policies used to shape them, and the framework within which they operate presently, will be analyzed in this Chapter. To that end, the economic, medical, ethical and socio-legal underpinnings of the frameworks or models for decision making will be examined critically as well as the conflicts and challenges arising from their application.

The vast complexities and philosophical nuances of the subject area, together with limitations of space imposed, dictate – necessarily – an analytical approach that is restricted in the scope and depth of its criticism. What will emerge from this Chapter, however, is a foundational evaluation of the core considerations, or perhaps principles, which – of necessity – guide in conflict resolutions regarding allocations of health care resources. These considerations, in turn, need to be addressed and, where appropriate, re-evaluated to assure that – to the extent possible – a level of distributive justice can be achieved in accessing and distributing limited health care resources to all citizens within the national, global or transnational communities.

INDIVIDUAL OR COMMUNITARIAN RIGHTS?

Americans assume that, as part of their inalienable rights to life, liberty, and pursuit of happiness, any health care plan sponsored by the government must validate and thus support these fundamental rights which in turn support their claim to whatever courses of action necessary to make them healthy and happy (Annas, 1998, 44). Thus, "essential care" or a "decent minimum" of health care is thought to be an integral part of the very right to health care. (Kilner, 1995, 1070). These claims of access to health care are all set within a culture that is technologically driven, individualistic, wasteful, and death denying; (Annas, *id.*) And one that refuses to accept limits to health care. (Gaylin (b), 1993).

The net effect of the near compulsive obsession with "rights talk" or the supremacy of the "ethics of rights" in health care, has challenged both the width and depth of the common or community life. The common good is, thus, compromised – all in order to advance or maintain private entitlements to more and more health "products." (Glendon, 1991; Etzioni, 1994). These products are in ever growing abundance because of the phenomenal successes of medicine, not its failures (Gaylin (b), 1993, Gaylin (a), 1996).

Since the potential demand for health care is virtually unlimited, finding a compromise between demand and supply associated with the distribution of scarce resources presents one of the most serious ethical problems of the day. (Havighurst et al., 1998, 179; Mason et al., 2002, 364). Sadly, medicine is today little more than a very, very expensive article of commerce. (Rodwin, 1993).

In contemporary society, medicine is seen as a marketplace – where emphasis is not only placed on entrepreneurship, efficiency and profit maximization, but upon customer satisfaction and ability to pay. Thus, the ideology of medicine is displaced by the ideology of the market place. Trust is replaced by *caveat emptor*. (Annas, 1998, 46; Pellegrino (a), 2001).

In order to correct this imbalance, patients must be placed at the center of the health care marketing system. Today, the focus in health care maintenance is on organizations instead of individual physicians. Individual-oriented medicine is thus, being displaced by "institutionally practiced, community-oriented health care." (Khushf, 2000, 148, 162). As a consequence, the dialogue and dialectic between the medical profession and the society it serves is strained. (Pellegrino (a), 2001; Brazier, 2003).

A Societal Shift?

It has been posited, perhaps rather wistfully, that society is moving slowly from materialism – where economic values control – to post materialism, where other values such as ethics are as significant. (Somerville, 2000, 259). If ethics have relevance, however, it is to be found within the principle of distributive justice which seeks a fair way to distribute scarce commodities. (Pellegrino 2001 (b), 78).

Within this new idealized environment, individualism is not recognized as the sole basis for rights. Rather, when taken together with individual responsibilities, individuals recognize responsibilities to the community and engage with a spirt of activism to fulfill those obligations. (*id.* 259).

It makes good sense to realize that since individuals form part of any and every community, they must assume their fair share of the burden of paying for the cost of the community's health care in an equitable manner. In this way, accessing health care is seen as a "special public good" – one grounded as such in basic principles of justice as well as on the basis that respect for persons and their essential human dignity requires communal action in order to safeguard the good, itself. (*id.* 268).

Moral traditions, thus, can be seen as not only undergirding, but defining, the "common community." (Childress, 1997, 241). Ultimately, there can be "no true common good if all do not have the good in common." (Kilner, 1995, 1071).

CONFLICTS IN DISTRIBUTION

Economic Issues

"Honest economists" have given up their efforts to develop an "overarching theory of distributive justice." (Hall, et al., 2003, 91). The quest for the achievement of this goal is, instead, left to ethicists, philosophers and ultimately public policy advocates. Libertarian philosophers see individual liberty as the predominate social value which can never be traded off, while egalitarian philosophers espouse "quality of opportunity" as the central or foundational value of a just society. (*id.* 91). It remains for public policy advocates and especially politicians, to listen carefully to the language of the law and the competing voices of religion and morality, love and friendship, custom and compromise, and of pragmatism and social accommodation (*id.* 71) in trying to fashion a sustainable social compromise from these struggles for access to and maintenance of health care. (*id.* 93).

Because of rising health care costs during the past fifteen years, societal concern has focused on whether the world's healthcare resources are being distributed fairly and wisely. More and more, contemporary medicine demands of its practitioners – particularly those in America – that the principle of justice be made a distinct factor in the decision making process (Andereck, 2000). Increasing governmental pressures continue to stress the need to follow cost control policies, eliminate waste and inefficiency and – as noted – implement the principle of distributive justice in patient care. As a consequence of these three competing policy concerns, more and more, patient interests become secondary to healthcare delivery (*id.* 236; Callahan, 1987(c)). The central conflict for physician-gatekeepers, who are responsible for seventy-five percent of the national expenditures for health care, (Pellegrino and Thomasma (b), 1988) thus, is to assure and maintain a patient-centered ethic in their professional work while, at the same time, from a *macro* economic standard, safeguard their responsibility to preserve society's resources (Andereck, 2000, 236). Ancillary to this conflict is the harsh reality that implementing distributive justice at the patient bedside, without any real societal consensus on how it is defined and practiced, most often means that an arbitrary process is put in place which depends upon – to a very large extent – the individual value system of the person assigning worth to the medical intervention or procedure put in issue – normally, the physician, (*id.* 236; Pellegrino and Thomasma (a), 1993).

In considering applications of distributive justice, then, physicians are required to evaluate this operative principle at two levels: the statistical patient or the identifiable patient (Andereck, 2000, 236). The more direct example of statistical applications of distributive justice is seen within the process of establishing guidelines for utilization review. Another example is found in the work of capital budget committees. Although decisions made under utilization and budget reviews affect, assuredly, real people, it is considered more appropriate and – indeed – safer by physicians to consider and evaluate their rationing decisions prospectively rather than be forced to evaluate issues of this nature at the bedsides of their patients (*id.* 237).

Alternatively, when the particular financial resources of each patient are factored into their identifiable medical treatment profile, the second and unstable level of distributive justice is seen in bold relief which may well involve bedside rationing. (*id.* 237).

Despite widespread differences among countries in the world community in their financing and organization of healthcare delivery systems, a common observation has been that all countries have a similar problem maintaining efficiency. This problem entails meeting cost inflation in healthcare expenditures. Efficient use of resources in medical care (or in any other field for that matter) requires that the benefit from the last dollar spent in any activity be no lower than the benefit obtainable from spending an additional dollar on some other procedure or from some other patient. Stated another way, if allocations of healthcare resources were totally efficient, it would be impossible to increase total medical benefits by diverting any money away from one service, for example, chemotherapy, and spending it on another, such as radiology (Aaron and Schwartz, 1984). Thus, most economists hold that treatments should cease when marginal benefits equal marginal cost (Menzel, 1990, 3).

Interestingly, in Britain, countless patients with chronic renal failure die earlier than necessary due to lack of dialysis treatment facilities. Yet, large expenditures are made routinely to prolong the lives of metastic cancer patients for brief periods (Aaron and Schwartz, 1984; Frankel and West, 1993). Thus, a rationing of care, to some stated or unstated degree, is seen in all health systems, and a conflict of approach as well (*id.* 84). For at one level of analysis is the outright denial of economic efficiency as any valid factor in medical practice and, at another level, a recognition that there is a moral impetus behind efficiency. Those who hold the second view conclude correctly that it would be unethical, and indeed fanatical, to foster an approach that allows one person to consume healthcare resources regardless of benefits conferred while totally ignoring other more valuable and directly beneficial uses of the resource (Menzel, 1990, 5).

Rationing policies encounter the most difficulties in the area of marginally beneficial healthcare. The reason for this is simple: it is quite difficult and distasteful to fine-tune rationing policies to the degree that they select the treatments, diseases, and people for whom marginal benefits are as great as opportunity costs (*id.* 7). Quite often age is a quotient in determining success of treatments and, at the same time, a factor in discrimination of healthcare delivery (Dubler and Sabatino, 1991; Wicclair, 1993).

RATIONING AS A FACT

Rationing has been in effect for quite some time and may be seen in three particular settings (Weinstein, 2003). First, it is implicit in all systems where limited amounts of money are available for healthcare and it is practiced daily by clinical physicians who must decide how resources will be used as each case is presented. This is the method of practice in prepaid health insurance programs, and so long as there are sufficient funds, the front-line physicians will have few challenges made to their clinical judgments. When third parties fail to fund specific treatments indicated medically, explicit rationing occurs. Even though physicians may be of the mind that certain medical procedures or surgical interventions are indicated, these treatments cannot be undertaken unless the patient can either fund them privately or prevail upon the doctor to complete them free of charge. A system of this design eliminates totally physician discretion for all items explicitly prohibited (Ubel, 2000).

For those individuals who have both money and health insurance, the market place itself structures methods of rationing that include copayments and deductibles, which force upon patients the ultimate decision whether they are willing to expend additional monies in order to obtain specific care. Consequently, for those citizens who are strained economically or without funds at all and are ineligible for public assistance, rationing of health services is not even an operable issue. There is no access to it at all! Sadly, it has been estimated that 15.2 percent of the population, or 43.6 million Americans, were without health insurance coverage during the entire year in 2002 – up from 14.6 percent in 2001, an increase of 2.4 million people (U.S. Census Rpt., 2003).

Those individuals qualifying under the income criteria for Medicaid programs have few problems with access to the healthcare delivery programs or the costs thereunder because virtually everything their physician recommends is available – so long as the monies allocated within the program last. (Smith (c), 1996). It has been thus suggested that – to the extent health problems can be regulated – serious illnesses should be presented at the first part of each fiscal year. Many families that are not wealthy still find that their income levels exceed the qualifying levels for membership in public health programs and are denied consequently even a minimum level of the most critical care because they simply cannot pay. It has been suggested further that by eliminating some of the available benefits of the Medicaid program not judged to be as important as others, funds could then be released so more people could become eligible for coverage even though overall fewer benefits would be available (Smith (c), 1996).

Specific Decisional Frameworks

Since no resource is infinite (and health resources are among them), selective distribution is inevitable. When considering issues of health care allocations, two classifications or levels of decision making are seen: microallocation and macroallocation. (Kilner, 1995, 1067). While *micro* issues are often regarded as "patient selection issues," or "choices among patients," regarding the resources available for specific kinds of health care services, (*id.* 1067, 1075), *macro* issues are focused on highly political matters such as the amount to which a nation is devoting its health care resources to primary and preventive care – as opposed to new biotechnology medicine – as well as the budget percentages being expended by hospitals. (*id.* 1067; Mason, 2002, 366).

Lacking a clear and unambiguous definition of rationing, it may nonetheless be seen as a process whereby some are – temporarily and against their wishes – left without types of health care that would otherwise provide a benefit to them (Kilner, 1995, 1067). In addition to referring to these general limitations, rationing may encompass, as well, very "specific treatment decisions for particular patients" at the bedside. (*id.* 1075; Hall et al., 2003, 98). Alternatively, rationing is seen as a means of providing every citizen with a guaranteed level of basic health care – this by excluding from coverage those treatments considered to be "outside" the package. (Blank, 1997, 96). On point in this analysis is certain: rationing is the central health care policy issue of the day. (Hall, *id.* 98).

Long viewed as haphazard and unprincipled, rationing occurs today as it always has. (*id.* 96). Yet, the term is softened considerably by referring to it as allocations of health care resources. (*id.* 96). No doubt the most direct example of massive rationing is to be found in the field of health insurance which is denied routinely to those who lack it because they work for an employer who simply does not provide it or because their personal level of poverty has yet to fall to that level required for eligibility under Medicaid. (*id.* 96).

The fundamental question raised in issues of health care resource allocation is, as seen: who decides what care is not worth the costs? The decision maker can be the patient, the physician or third parties (primarily private and governmental insurers) (Rodwin, 1993). Two central approaches are considered normally: those oriented toward achieving the most productive use of the health resources and those designed to ensure equality of access to treatment through impartial or random selection for all suitable candidates. (Kilner, 1995, 1082)

Among the specific criteria used in determining proper *micro* allocations are: social value (with treatment preference being given to those judged of greatest social value to society), socio-medical (*e.g.,* age), psychological balance, nature and quality of supportive environment, medical (determining the basic merits or extent to which a benefit is conferred) and personal (the patient's willingness to accept treatment). (*id.* 1076–1081; Mason, 2002, 380–381).

Among the approaches to rationing used widely are: "first come, first served" system of queues, random selection (which takes no account of the gravity of either the patient's conditions or of the medical benefit), ability to pay, *triage* systems based on medical urgency and – more recently – systems tied to computations of quality adjusted life years (QALYs) which are designed to test the appropriateness of treatment. (Blank, 1997, 96; Mason, 2002, 379–386). It has been suggested that treatment considered to be unsafe, unkind, unsuccessful or unwise is inappropriate and should be withheld. (Blank, 1997, 96).

At the *micro* level, *ad hoc* decisions are made routinely and instinctively without need for any profound analysis. Accordingly, the bedside physician will inevitably choose the patient in greater pain for appropriate treatment – this, despite the fact that his will delay simultaneously the treatment of patients in lesser pain. (Mason, 2002, 378).

Interestingly, there is no precedental case law measuring societal attitudes with respect to judging the allocation of resources at the *micro* or individual level – since, presumably, decisions are taken in good faith and are based on principles seen as respectable to a responsible body of medical opinion (Mason, 2002, 385).

In considering how to limit the use of healthcare costs, ethical conduct which respects one's autonomy and his right to decide for himself those treatments that he wants or, alternatively, does not wish, can well lead to a reduction in costs. Minimally life prolonging treatments which are also invasive and expensive are often refused. Education in "lateral thinking" can also effect cost and resource savings. Thus, assisting individuals to deal with their death fears by offering palliative care options, presented a wider range of potentially cost-saving choices available for the care and treatment at the conclusion of their lives. (Somerville, 2000, 262).

Other decisionmaking mechanisms for health care resource allocations are found in internal hospital policies – for example, those that set standards for use of do not resuscitate orders. It is within these internal guidelines that institutional policies are in turn formulated. (*id.*). As well, hospital ethics committees serve as an important source for setting policies which govern not only access to health care, but to allocations of health resources and egress therefrom. (*id.* 272–273; Smith (e), 1990; Gaylin (b), 1993). Through medical malpractice decisionmaking, the courts also become a mechanism and structure for determining efficacious uses of resources. (Somerville, 2000, 274; Moore v. Regents of University of California, 1990). Finally, healthcare advocacy groups are becoming a growing and forceful voice in resource management here. (*id.* 274).

Prioritization

The pressing question, if such a change as this is advanced, is how to determine those benefits that could be retained. The clearest and most direct approach to resolving this question would be to assemble – as the state of Oregon did – a group of experts or health commissioners to develop a list, in order of importance to health, of medical procedures and surgical interventions. This, then, is labeled *prioritization* or, alternatively, rule-based rationing. (Blank, 1997, 98). A cut-off level could be set by the legislature or even by a private insurance company. Although a legislature would simply make the cut-off (the limit for present or even future funding determined actuarially for the number of citizens eligible in the state), private insurance companies would probably use this priority list by writing policies at different rates and then offering them for various cut-off points on the list (*id.* ch. 4; Strosberg, Wiener et al., 1992).

In the event a legislature chose a cut-off point on the priority list where the population covered by the program was being denied beneficial healthcare, this could be termed properly *rationing.* (Gaylin (b), 1993). Similarly, the private insurance company could be thought of as rationing according to the levels private citizens could afford to pay for themselves. Certainly it is not unfair, in any sense of the word, to expect some limit for a public health program of this design – especially if the program were not restricted unconscionably (Robinson, 1992). Indeed, it can be argued persuasively that because public funds are expended on healthcare in recognition of the social good attached to health maintenance, society has every right to administer and control the monies expended in order to assure their wise and just allocation.

Necessary Healthcare Need Variables

Rationing can be avoided as a national policy if an agreement can be reached in identifying "really necessary" healthcare interventions and a process was then designed to ensure that all patients have equitable access to them. Thus, objective criteria, which could possibly take the form of clinical guidelines, must be established and identify real healthcare needs, as opposed to mere desires. These guidelines would be termed "necessary care guidelines" and would give the indicators or types of patients for whom specified services would be considered necessary. Applied as standards of care, these guidelines would specify patient management strategies required for patients with certain medical problems. Physician adherence to these guidelines would serve as a defense in a malpractice action (Hirshfeld, 1992). Ideally, these policies or guidelines would be developed by bodies or panels drawing on outcome data, public testimony, and expert consensus. In measuring treatment, *net benefit* would be defined in terms of longevity plus quality of life (Hadorn and Brook, 1991).

Ethics of Rationing Healthcare

Richard Lamm, in suggesting a working ethical principle for distributing healthcare resources for the elderly, created quite a furor among the elderly when he urged healthcare resources be distributed along a utilitarian principle so as to maximize the long-run general happiness of the entire community and not only the debilitated, chronically ill, or very elderly as individual members of it. In other words, he argued that the greatest health resources should go to the greatest number of individuals capable of using them effectively. The reality of this harsh statement meant that, in Lamm's view, the elderly have "a moral duty to forgo further healthcare and to accept their death" (Waymarck, 1991). Children, he maintained, have more opportunities to flourish and achieve happiness; therefore, it was only logical that they should deserve a greater share of health resources than the elderly. This, of course, once again raises the issue of intergenerational equity or justice.

A society surely cannot consider itself a noble one if it does not respect the individuality of its members – even when to do so creates the appearance of running counter to the general happiness of the community at large. Any society runs the risk of dividing itself if it seeks to withhold healthcare from the elderly based on the argument that the "return" of such an investment can never be realized economically because of the limited lifespans of the recipients. The Lamm thesis challenges society to reallocate its healthcare resources in a way that does not abandon the elderly yet achieves a balance in providing long-term health protection and happiness for its members as a whole. Sadly, current evidence discloses that this challenge is going unmet (*id.* 195–97).

PATTERNS OF MODERN RATIONING

Renal dialysis and heart transplantation are perhaps the two most relevant examples of contemporary rationing. When dialysis was in its infancy, it was a scarce and costly intervention with only a few dialysis machines in existence. In efforts to develop a scheme for the use of this new, scarce life-saving technology, different localities adopted varying policies for determining who should have access to the technology. In Seattle, Washington, social worth was used as a criteria in the decision-making process to decide ultimately on the relative value of the lives of those individuals competing for use of the process itself. When Congress was presented with this problem, it simply expanded Medicaid coverage to provide kidney dialysis for all patients in need – with average costs now running in excess of $1.5 billion per year (Dubler and Sabatino, 1991, 114).

Although recognizing *de facto* rationing as a current feature of contemporary healthcare delivery systems, any further expansions of it should be delayed, it has been suggested, until the irrationalities of the current national system are resolved (Maguire and McFadden, 1994). This suggestion is impractical simply because rationing is seen as inextricable (if not unavoidable) given in the present system and its "irrationalities" are beyond correction within any reasonable period of time. Others might suggest that this effort to distribute scarce resources in an equitable manner, that is, rationing, is not irrational at all (Haddad, 1994).

Because healthcare services, providers of healthcare, and the means to pay for these services are all scarce, procedures must be established and followed to allow for a fair distribution of them. As observed, physicians engage regularly in rationing by their regulation of the extent of participation in Medicare as well as in health maintenance organizations (HMOs) (*id.*). Historically, during times of military engagement, field physicians decided routinely whom they would treat because they were "salvageable" and those from whom treatment would be withheld until the others were treated. Some were even denied treatment because of the futility of such actions. And, even today, emergency medicine – as practiced in emergency wards of major hospitals and in times of local or state disaster – utilizes the principle of *triage* (Smith (f), 1985; Smith (d), 1996). A strong argument could be advanced that, indeed, the very bedrock of modern rationing is to be found, to one degree or other, within the principle of *triage*. Surely an analogy can be seen between a military battlefield and the crisis in healthcare management because in both, efforts must be made to balance the costs with the benefits of all actions taken (Callahan (b), 1990; Callahan (a), 1992).

The Value of Life

Economists seek to place an actual monetary value for people's lives by employing two models. The first, called the human capital model, calculates the value of life only in terms of productivity or the present discounted values of one's future earnings. The second model is described as willingness to pay. Here, the monetary value of life is directly a function of one's willingness to use resources to increase one's chance of survival. Thus, in a hypothetical situation in which an individual annually demands an extra $500 in order to perform work that runs an additional 1-in-1,000 risk of dying, $500,000 is the monetary value of that person's life. No more than $500,000 need be spent under this hypothetical model to save a particular life (Menzel, 1990, 38; Perett, 1992).

Measuring Quality of Life

A controversial, albeit growing, view in health economics is that the goal of all service should be to create as many years of healthy life as possible for as many as possible. The underlying basis for this view is, quite simply, the "assumption that for all a like a year of healthy life is equally valuable" (Menzel, 1990, 79). The productivity of healthcare, then, is measured in terms of years of healthy life or quality-adjusted life years (QALYs). Thus, when consideration of the cost of receptive treatments is combined with the length of lives extended and the quality of life they enhance, interesting examples can be posited that force striking conclusions (Hahn and Wallstein, 2003). For example, because hip replacements produce QALYs at approximately one-twentieth the cost of renal hemodialysis, the conclusion is obvious: more replacements should be done. Using the same principle, there should also probably be more coronary bypass surgeries for individuals with severe angina and left main vessel disease and more screening and follow-up treatment for mild hypertension because of the qualitative results that follow these procedures (Menzel, 1990, 80).

The aged are disadvantaged significantly by QALYs – this, because quality-adjusted life years measure only treatment endpoints without taking into consideration either the proportional loss or the gain in the quality of one's life. Thus, the major moral criticism of QALYs is that they set no value on life *per se*. (Mason et al., 2002, 382).

An alternative to QALYs has been suggested in what is termed, "the saved young life equivalent." (*id.* 382). Although, arguably, still reducing individuals to numbers, this approach seeks a unit of measurement in which saving a young person's life and restoring him to full health is the controlling paradigm. This position is justified on the grounds that most people would regard this goal, itself, as the maximum benefit an individual can gain. (*id.* 382). An assessment of comparative treatment values is thus made "in terms of how many expected outcomes of each treatment would be equivalent to SAVE." (*id.* 382). Instead of trying to structure a model that seeks to incorporate a defensible method of pricing life and health, QALYs are thought to be a more feasible means of prioritizing healthcare services. The goal of trying to obtain the most QALYs from a healthcare system does not force a search for an answer to the central question: namely, what amount of money should be spent per QALY. Thus, quality-adjusted life years will be of considerable use in those contexts in which the question of the amount of resources to spend on healthcare has presumably been answered; that is, when there is a health budget to stay within such as in the British National Health Service, an American prepaid plan, or in a rational Medicare plan operating in the 21st century (*id.* Anderlik, 2001, 54–55). Indeed, some speculate that soon within this century, QALYs will be accepted totally and used in planning and organizing health services (Menzel, 1990, 80–81).

Risk-Benefit or Cost-Benefit Analysis

Perhaps the fairest idea for limiting or rationing care is to be found in risk-benefit analysis, which shows the risk and potential benefit of a medical procedure. (Kilner, 1995, 1073). In developing risk-benefit uses, although age might always be expected to weigh against an older person likely to have fewer years of vigorous life left, it would not be necessarily conclusive (Smith and Rother, 1992). If, for example, a very elderly man with an aneurysm, failing kidneys, and other complications were presented for surgical evaluation, under a cost-benefit analysis, a decision regarding the merits of surgery would be simply tied to cost. Under risk-benefit analysis, if the likelihood the patient's surviving surgery were practically zero, whereas the likelihood of his living very long even if he did survive the surgery was very low, then surgery to repair the aneurysm would not be found probably cost-effective (Rich, 1990).

An Ethical Dilemma and the Americans with Disabilities Act

Rationing on the basis of quality of life – as opposed to cost, effectiveness, or cost-effectiveness – has a strong civil rights advantage; it seeks to measure the value of life to the individual patient as opposed to his usefulness to society. The inherent complexity with this is determining and, thus, adhering to an incompetent patient's life preferences. In those cases where these are not fully determinable, a substituted judgment model is used. Accordingly, the surrogate decisionmaker construes patient preference and makes a decision the patient would have made if competent. Rationing at this level forces an ethical dilemma: specifically, quantifying the value of life for individuals in varying states of disability and health. Because quality of life decisional standards are subject to being colored or influenced by prejudices toward disability, it could be argued that this standard of rationing might well be considered discriminatory and, furthermore, violate the purpose of the Americans with Disabilities Act (ADA), which was designed to eliminate differential treatment based on disability (U.S. Code, 1991; Stode, 1993), and thus effect a redestribution of scarce goods so that the disabled receive additional resources to compensate for their limitations (Hoffman, 1219–22).

Although yet to be tested definitively in the courts, the ADA's definition of discrimination appears to proscribe implementation of any theory (or healthcare measure) that advances the notion that the quality of life associated with a treatment should in part determine the priority given to funding the treatment itself. In order to avoid further confusion on this issue, Congress should act decisively to amend the ADA, thereby allowing the states to deal directly with the issue of scarce healthcare resources and make whatever rational choices are necessary and base them on the most reliable and available measure of qualitative life (Thomasma (e), 1990; Stode, 1993).

STRUCTURING A DECISIONAL FRAMEWORK?

Establishing fair procedures for the distribution of health care resources is a crucial goal for contemporary society to set and, hopefully, to achieve. Accordingly, fairness is to be defined and shaped by four conditions: (1) public accessibility to "limit-setting decisions" and their policies and rationales; (2) clarity in policy rationales which explain how "value for money" is met in distributing health care resources within a society where there are reasonable resource constraints on the resources themselves; (3) a framework for principled decision making which provides a means for resolution of disputes; and (4) a regulatory process which not only assures public access to the initial "limit-setting decisions" but also provides an equitable mechanism for challenging the reasonableness of contested health care distribution decisions (Anderlik, 2001, 134).

Restoring Trust

Sadly, as a direct consequence of the multiple and conflicting roles a physician is cast in or forced to choose between, because of either the particular managed care program he is practicing under or the professional ethic he espouses, medicine is no longer being seen as caring for people. Indeed, the very acceptance of medicine as a moral value whose end is the healing of vulnerable persons is need of life and whose paramount essence is codified in the virtue of benevolence, is thus challenged to its very core (Thomasma (c), 1998, 335–36).

The politics of economic self-interest compromise – if not extinguish – the sacred trust patients once placed in their physicians. Stated otherwise, the present system promotes the use of expensive, invasive and at-risk treatments and places little effort in patient care. It has been suggested that a new ethic needs to be recognized and embraced by physicians – one that shifts from using medicine if it might assist to one that promotes use only when it will (Anderlik, 2001, 5).

Balancing Needs Within The Democratic Process

The ineluctable conclusion to be drawn from this analysis is that in formulating health care policies, the principle of distributive justice demands decisions such as allocating and rationing health care be made fairly within the political process. It demands, further, that broad grants of discretion (which in turn often promote managerial indecision) to administrative decisionmakers in the HMOs who, themselves, have varying systems of values, and to bedside medical gatekeepers as well, be limited. It is only by and through deliberate debate within a democracy that assumptions about aging, the value of life for the aged and intergenerational responsibilities of assisting them in their care can be set, tested or – as the case may be – rejected (Smith (b), 1999, 102–03).

"Most people," it has been said, "are ignorant about most matters." (Posner, 1990). This is true particularly with regard to the health care market where consumers are found to be lacking in basic information about not only the quality, but the price of medical services. This ignorance, in turn, means consumers lack the expertise to evaluate the professional qualifications of health care providers as well as evaluate necessary information regarding the range of alternative treatments available to them. Even when price information is available, health care consumers have difficulty assessing and, indeed, comprehending what the data means and how it impacts on their accessing health care. (Furrow et al., 2001, 478).

Since the efficient use of medical resources dictates both consumers and health care providers weigh the costs and the benefits of alternative medical treatments, the failure to access health care information regarding these options means – essentially – that physician preferences for particular medical procedures trump the ideal of informed patient consent. (*id.* 479). And, this in turn, means that the physician solidifies his position of power as the primary gatekeeper to health care resources.

In the final analysis, what is called for is fair democratic procedures designed to allow average citizens to be sufficiently informed and knowledgeable in order to make choices among just alternatives for health care resource allocations. (Childress, 1997, 254). Aided by careful cost-effectiveness and cost-benefit analyses, tied – as such – to those discernible values ranked clearly as beneficial and those regarded as costly, such a process can in fact work. (*id.*)

Granted, a public dialogue to reach a *consensus* on how medical resources ought to be distributed is unlikely (Berger et al., 1996; Blank, 1997, 98). Yet, a "public conversation" on these issues of the type the state of Oregon undertook several years ago is available. No matter within what policy forum the health care resource debate occurs – local, state, or national – a fundamental balancing test will, of necessity, be employed; one that weighs, in an equitable and reasonable manner, individual needs with larger societal standards of economic efficiency (Anderlik, 2001, 130). By seeking to integrate moral and ethical reasoning with quantitative or economic formulations of needs and resources, the opportunities for a stronger and more contemporary standard of distributive justice will be both enhanced and stabilized (Pellegrino and Thomasma (c), 1981).

The ultimate moral issue seen in this debate is not – rather surprisingly – whether too much or too little treatment is offered; but rather how to seek an optimum level of reasonable or appropriate treatment based on the medical condition of each patient. Failing to meet resolutely the inherent difficulty of allocative decisions here foredooms the total decisionmaking process to a continued state of lethargy where inaction becomes the tragic hallmark of health care management.

CONCLUSIONS

In the final analysis, it is quite possible (and probable) that society has come to review health care as little more than but a commodity – a service – much as other commodities in a market economy and for which specific and harsh rationing decisions are imposed on physicians. The direct consequence of this societal re-direction means the cornerstones of professional medical ethics – beneficence, patient autonomy and justice – will yield to "social good and economic need" (Pellegrino and Thomasma (b), 1988, 187). The whole art of healing, once seen as a partnership between the healer and nature, itself, is also thus recast as an effort to redesign nature – improving upon it, and aiming it in new startling directions heretofore not found in its history (Thomasma (b), 2000, 135).

The choice implied, inherently, in the rationing of medical goods and services "will reveal more about the kind of people we are, and wish to be, than it would about the ideas we profess" (Pellegrino and Thomasma (b), 1988, 185). Indeed, there is a growing national belief in, and acceptance of, the inevitability of rationing and an awareness of the attendant ethical issues and dilemmas deriving therefrom within the patient-physician relationship (*id.*) – issues arising inescapably from the very nature of managed care which, itself, challenges the foundational basis of relationship centered care (Thomasma (d), 1996).

From a transnational perspective, perhaps it is more realistic – when considering the extent to which there should be a governmental obligation to guarantee a citizen's good health – to refer to a right to health protection – with this including a right to access health care together with a right to live under healthy conditions (Smith (a), 2000, 16). Ideally, guaranteeing access to health care resources is the foundation upon which all other assertions of health care "rights," and their permutations are built. Lacking a strong determinative framework for both identifying and analyzing the essential societal factors representing the conditions under which people can access health care, it is thought unrealistic and impractical to acknowledge an absolute right to health care (*id.*). International legislative templates go only so far in shaping a response to this issue. Rather, the dynamics of gatekeeping ethics and the centrality of the medical healing partnership between patient and physician must be seen as the paramount elements in assuring distributive justice both in the national and transnational health care delivery system (Pellegrino and Thomasma (c), 1981; Pellegrino and Thomasma (a), 1993).

REFERENCES

Aaron, H.J. and Schwartz, W.B. (1984) *The Painful Prescription: Rationing Health Care* (pp. 83, 89). Washington, DC: Brookings Institution.

Andereck, W. (2000) Money Medicine and Morals. In D. Thomasma and J. Kissell (Eds.), *The Health Care Professional as Friend and Healer: Building on the Work of Edmund D. Pellegrino,* (pp. 233–235). Washington, DC: Georgetown University Press.

Anderlik, M. (2001) *The Ethics of Managed Care: A Pragmatic Approach* (p. 125). Bloomington, IN: Indiana University Press.

Annas, G.J. (1998) *Some Choices: Law, Medicine, and The Market* (pp. 12–51). New York: Oxford University Press.

Berger, P.L., Neuhas, R.J., and Novak, M. (Eds.). (1996) *Empower People: From State to Civil Society.* Washington DC: AEI Press.

Blank, R.H. (1997) *The Price of Life,* ch. 4. NY: Columbia University Press.

Brazier, M. (2003) *Medicine, Patients and The Law,* ch. 2. London: Plenum

Callahan, D. (1992a) Symbols, Rationality and Justice: Rationing Health Care. *American Journal of Law and Medicine,* 18, 1–13.

_________. (1990b) *What Kind of Life: The Limits of Medical Progress.* NY: Simon and Schuster.

_________. (1987c) *Setting Limits: Medical Goals in an Aging Society.* NY: Simon and Schuster.

Childress, J.F. (1997) *Practical Reasoning in Bioethics.* Bloomington, IN: Indiana University Press.

Dubler, N. and Sabatino, C. (1991) Age-based Rationing and the Law: An Exploration. In R.H. Binstock and S.G. Post (Eds.), *Too Old for Health Care? Controversies in Medicine, Law, Economics and Ethics,* (p. 92). Baltimore, MD: Johns Hopkins University Press.

Etzioni, A. (1994) *The Spirit of Community*. NY: Touchstone Press.

Frankel, S. and West, R. (1993) *The National Health Service: The Persistence of Waiting Lists*. Houndmills, Basingstoke Hampshire, UK: Macmillan.

Furrow, B.R., Greaney, T.L., Johnson, S.H., Jost, T.S., and Schwartz, R.L. (2001) *Health Law* (pp. 473–485). St. Pau, MN: West.

Gaylin, W. (1996a) Health Unlimited. *The Wilson Quarterly*, 20, 38–42.

_________. (1993b) Faulty Diagnosis: Why Clinton's Health-care Plan Won't Cure What Ails Us. *Harper's Magazine*, 287, 57–65.

Glendon, M.A. (1991) *Rights Talk: The Impoverishment of Political Discourse.* NY: Free Press.

Goodhart M. (2003) Origins and Universality in The Human Rights Debate: Cultural Essentialism and The Challenge of Globalization. *Human Rights Quarterly,* 25, 935–964.

Haddad, A. (1994) Ethical Issues in Health Care Rationing. In K. Kelly (Ed.), *Health Care Rationing: Dilemma and Paradox,* (p. 11). St. Louis, MO: Mosby.

Hadorn, D.C. and Brook, R.H. (1991) The Health Care Resource Allocation Debate: Defining Our Terms. *Journal of the American Medical Association*, 266, 3328–3331.

Hahn, R. and Wallstein, S. (2003) Whose Life is Worth More? And Why Is It Horrible to Ask? (*Washington Post*, June 1, 2003, (p. B3)).

Hall, M.A., Bobinski, M.A. and Orientlicher, D. (2003) *Health Care Law and Ethics* (pp. 68–98). New York: Aspen.

Havighurst, C.C., Blumstein, J.F., and Brennan, T.A. (1998) *Health Care Law and Policy* (p. 179). NY: Foundation Press.

Hirshfeld, E. (1992) Should Ethical and Legal Standards for Physicians be Changed to Accommodate New Models of Rationing Health Care? *University of Pennsylvania Law Review*, 140, 1809–1843.

Khushf, G. (2000) Organizational Ethics and The Medical Profession: Reapprising Roles and Responsibilities. In D.C. Thomasma and J.L. Kissel, (Eds.), *The Health Care Professional as Friend and Healer: Building on The Work of Edmund D. Pellegrino* (p. 148). Washington, DC: Georgetown University Press.

Kilner, J.F. (1995) Allocation of Health Care Resources. In W.T. Reich (Ed.), vol. 2 *Encyclopedia of Bioethics* rev. ed. (pp. 1067–1084). New York: Simon and Schuster

Kunneman, R. (1995) A Coherent Approach to Human Rights. *Human Rights Quarterly,* 17, 323–342.

Maguire, D.C. and McFadden, E.A. (1994) The Ethics of Health Care Rationing. In K. Kelly (Ed.), *Health Care Rationing: Dilemma and Paradox,* (pp. 149–54). St. Louis, MO: Mosby.

Mason, J.K., McCall Smith, R.A., and Laurie, G.T. (2002) *Law and Medical Ethics* (p. 364–386). London: Butterworths.

Menzel, P. (1990) *Strong Medicine: The Ethical Rationing of Health Care* (p. 3). NY: Oxford University Press.

Monagle, J.F. and Thomasma, D.C. (1988) *Medical Ethics: A Guide for Health Professionals.* Rockville, MD: Aspen Publishers, Inc.

Moore v. Regents of the University of California, Supreme Court of California, 51 cal.3d 120, 271 Cal. Rptr.146, 793 P.2d 479 (1990).

Paust, J. (1992) The Other Side of Right: Private Duties Under Human Rights. *Harvard Human Rights Journal*, 5, 51–63.

Pellegrino, E.D. (2001a) The Goals and Ends of Medicine. In R.J. Bulger, and J.P. McGovern (Eds.), Physician and Philosopher: The Philosophical Foundation of Medicine. *Essays by Dr. Edmund D. Pellegrino* (pp. 56–69). Charlottesville, VA: Carden Jennings Publishing Co. Ltd.

_________. (2001b) Access to Health Care. In R.J. Bulger and J.P. McGovern (Eds.), *Physician and Philosopher: The Philosophical Foundations of Medicine* (pp. 277–283).

Pellegrino, E.D. and Thomasma, D.C. (1993a). *The Virtues in Medical Practice.* NY: Oxford and University Press.

_________. (1988b) *For The Patients Good: The Restoration of Beneficence in Health Care,* (p. 189). NY: Oxford University Press.

_________. (1981c) *A Philosophical Basis of Medical Practice: Toward A Philosophy and Ethic of The Healing Professions.* NY: Oxford University Press.

Perett, R. (1992) Valuing Lives. *Bioethics*, 6, 185–196.

Posner, R.A. (1990) *The Problems of Jurisprudence,* (p. 112). Cambridge MA: Harvard University Press.

Rich, S. (1990) Official Suggests Risk-Benefit Rationing. *Washington Post Health Magazine,* Jan. 23, 1990, (p. 25).

Robinson, E. (1992) The Oregon Basic Health Services Act: A Model for State Reform? *Vanderbilt Law Review*, 45, 977–1014.

Rodwin, M. (1993) *Medicine, Money and Morals* (pp. 1–20). New York: Oxford University Press.

Simma, B. (1991) International Rights and General International Law: A Comparative Analysis. In IV *Collected Courses for the Academy of European Law,* Bk. 2, 153–236.

Smith, A. and Rother, J. (1992) Older Americans and The Rationing of Healthcare. *University of Pennsylvania Law Review*, 140, 1847–1857.

Smith, II, G.P. (2000a) *Human Rights and Biomedicine.* The Hague: Kluwer Law International.

_________. (1999b) Judicial Decisionmaking in the Age of Biotechnology. *Notre Dame Journal of Law,* Ethics and Public Policy 13, 93–120.

_________. (1996c) *Legal and Health Care Ethics for the Elderly,* ch. 4. Washington, DC: Taylor and Francis.

_________. (1996d) Utility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment. *Journal of Contemporary Health Law and Policy,* 12, 1–39.

_________. (1990e) The Ethics of Ethics Committees. *Journal of Contemporary Health Law and Policy,* 6, 157–170.

_________. (1985f) Triage: Endgame Realities. *Journal of Contemporary Health Law and Policy*, 1, 143–151.

Somerville, M. (2000) *The Ethical Canary: Science, Society and The Human Spirit* (pp. 226–269). Toronto, Ontario Canada: Viking.

Steiner, H.J. and Alston, P. (1996) *International Human Rights in Context,* (pp. 563–569). NY: Oxford University Press.

Stode, N.K. (1993) The Use of Quality of Life Measures to Rational Health Care: Reviving a Rejected Proposal. *Columbia Law Review*, 93, 1985, 2020–2021.

Strosberg M.A., Wiener, J.M., Baker, R., and Fein, I.A. (1992). *Rationing American Medical Care: The Oregon Plan and Beyond.* Washington, DC: Brookings Institution.

Thomasma, D. (2001a) Proposing A New Agenda: Bioethics and International Human Rights. *Cambridge Quaterly of Healthcare Ethics,* 10, 299–310.

_________. (2000b) The Principle of Dominion. In D.C. Thomasma, and J.L. Kissell, (Eds.), *The Health Care Professional as Friend and Healer: Building on The Work of Edmund D. Pelligrino* (pp. 133–147). Washington, DC: Georgetown University Press.

_________ . (1998c) Virtue Theory, Social Practice, and Professional Responsibility in Medicine. In M. Evans, (Ed.), 4 *Critical Reflection on Medical Ethics* (321–338). Stanford, CT: JAI Press.

_________. (1996d) The Ethics of Managed Care: Challenges to The Principles of Relationship Centered Care. *Journal of Allied Health*, 25, 233–246.

_________ . (1990e) Ethical Judgments of Quality of Life in the Care of the Aged. In J. Walter and T. Shannon (Eds.), *Quality of Life: The New Medical Dilemma,* ch. 19. NY: Paulist Press.

Ubel, P. (2000) *Pricing Life: Why It's Time for Health Care Rationing*. Cambridge, MA: MIT Press. *United States Census Bureau Rpt.* P60-223 (Sept. 2003). Wash., DC: U.S. Dept. of Commerce. 42 U.S. Code §§ 12201–12213 (Supp. III, (1991)).

Waymarck, M.H. (1991) Old Age and the Rationing of Scarce Health Care Resources. In N. Jecker (Ed.), *Aging and Ethics: Philosophical Problems in Gerontology* (pp. 248–249). Clifton, NJ: Humana Press.

Weinstein, M.C. (2003) We Ration Health Care: Better Do It Rationally. *Washington Post,* June 1, 2003, (p. B3).

Wicclair, M.H. (1993) *Ethics and the Elderly*, ch. 3. NY: Oxford University Press.

JULIO ARBOLEDA-FLÓREZ AND DAVID N. WEISSTUB

CHAPTER 21
MENTAL HEALTH RIGHTS: THE RELATION BETWEEN CONSTITUTION AND BIOETHICS

1. INTRODUCTION

In her January 15, 2005 statement to the Open-Ended Working Group of the UN Commission on Human Rights, Louise Arbour, UN High Commissioner for Human Rights, underscored the importance of expanding our vision, both nationally and internationally, of the scope of fundamental human rights:

> Recognizing the status of economic, social and cultural rights as justifiable entitlements is crucial to honouring the political, moral and legal commitments undertaken by States when the international bill of rights was adopted (Arbour).

Her comments, while reaffirming the conception of positive social entitlements as justiciable human rights under international law (as enshrined in such conventions as the *International Convention on Social, Economic and Cultural Rights*) underscore the failure of states to give meaningful effect to "second generation" rights. As a Justice of the Supreme Court of Canada, and a frequent dissenter with respect to the ambit of social rights under the *Canadian Charter of Rights and Freedoms*, Arbour has gauged the shortcomings of national legal systems in this respect.[1] Over the past several years, states have come to a growing realization of both the depth and cost of mental health conditions within their populations; this awareness has accelerated the momentum for mental health law reform. Such reforms, however, ought not to be restricted to operational questions on the adequate level of services, nor to the problem of financing, but should include a review of the human rights dimension of such systems. For, while the protection of the human rights of mental patients seems to have become a priority in the international arena, as evinced from the growing body of international law in this area, the actual plight of mental patients does not seem to have improved, and in fact, seems to be getting worse, largely as a result of neglect at the national level. This chapter surveys the status of persons with intellectual disabilities in the context of international law, and assesses this status in the Canadian context.

A distinction must be made between positive rights and entitlements. International sources of human rights recognize both negative and positive rights. Negative or "first generation" rights include those which preclude interference with a protected freedom, and prevent the state from certain proscribed action. Positive or "second generation" rights impose mandatory obligations upon states. Although the national systems of countries such as Canada provide significant civil and constitutional protections with respect to the positive rights of its citizens,

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 309–327.

including those who suffer from intellectual disability, the same cannot be said with respect to entitlements to the provision of social services (Hirschl 2000). The authors will argue that this shortcoming must be remedied; in particular, it is suggested that, while it might be preferable to improve the lives of those suffering from intellectual disabilities through justifiable means before the courts, this is not likely to happen. Thus it is preferable that advocates in Canada should focus upon administrative and legislative reform by Parliament and the provincial legislatures.

2. HISTORICAL LEGACY

Recent movements to advance the human rights of persons with intellectual disabilities have their genesis in the appalling abuses suffered by generations of mental health patients, ever since and prior to the birth of the asylum. Paradoxically, however, the birth of the asylum was in many respects the product of compassion: although the story may be apocryphal, the establishment of the first European asylum for the insane in Valencia in 1409 by Father Gilabert Jofré is said to have been motivated by Jofré's witnessing of the abuse suffered by a mental patient (Pinel 1988). However, what began as a refuge quickly developed into a prison, and resulted in what Luis Vives has described as institutionalized social exclusion (Vives 1980). Banishment through institutionalization was, of course, only a continuation of a more pernicious model of social management prevalent before the advent of the asylum in Valencia. The *Narrenschiff* or *Stultifera Navis*, the Ship of Fools, in which the mentally ill, according to Sebastian Brant, were condemned to navigate the waters of the rivers of Europe never finding a port, but always banished from place to place, preceded the asylum (Brant, 2005).

Socio-politically, the asylums, as Michel Foucault has indicated, replaced the leprosariums. But whereas the latter were exclusive for lepers, the asylums became the place of what Foucault baptized the "Great Confinement," that is, places for all sorts of undesirables, especially persons affected by mental conditions (Foucault 1988). In fact, the *lettres de cachet* contemplated in the 1838 *Act on the Insane* in France, which gave the "hospital archers" authority to round up and lock up, among others, "beggars, vagabonds, the chronically unemployed, criminals, rebel politicians, heretics, prostitutes, syphilitics, alcoholics, madmen and idiots" became the blueprint for similar institutions all over the Western world (Dörner 1974). The characterization of the mentally ill as "wild beasts" left no other alternative, but to put them away (Gracia and Lázaro 1992).

It has been a long struggle for the mentally ill to return from their banishment. Even gestures such as Pinel's, who, imbued with the libertarian ideals of the French Revolution, publicly cut the chains that held the mentally ill to their posts at La Saltpêtrière in 1795, have been insufficient as old and decrepit mental hospitals are still the preferred, and often only, model of care in many countries (Häfner 1991). And yet, removing their chains and allowing them to return to their communities has not resulted in meaningful liberation for most persons with mental disabilities. In most countries, even the most advanced and prosperous, mental patients are no longer in asylums, but in prisons, which have become veritable mental hospitals (Konrad 2002). Criminalization of persons with mental disorders is overregulated and overseen by courts of law and forensic psychiatrists who, in concert, have become the gatekeepers, or modern day superintendents (Arboleda-Flórez 2005). The process of forensic evaluations has become another filter for treatment that keeps mentally ill persons in limbo, ensconced among three seemingly inimical systems – the healthcare, justice and corrections. In the end, however, the effect of many forensic evaluations amount to the same reality – loss of liberty in a hospital for the criminally insane or deprivation of liberty in a jail pending legal dispositions. What have the mental patients gained (Weisstub 1985)?

3. INTERNATIONAL LAW AND THE RIGHT TO HEALTH CARE

International law has, in many respects, led the way in advancing the rights of mentally ill patients. This advancement has taken the form of both binding and non-binding international norms, as well as proposals for domestic legislative reform. International law finds its expression in either treaties or customary norms. The latter can take the form of bilateral treaties between state partners or multilateral conventions promulgated by international organizations such as the United Nations. Customary international norms, on the other hand, have their origins in state practice and *opinio juris* (Kinney 2001). Regardless of their source, human rights, including a right to health and social services, have figured prominently under international law. Human rights under international law have arguably made the furthest progress with respect to negative rights (that is, relative to states), although international law is beginning to constitute a source of positive entitlements.

The *International Covenant on Civil and Political Rights* (I.C.C.P.R.) has had a great impact on the promotion of negative rights with respect to persons with disabilities. This covenant, which has been ratified by 151 countries, including Canada as of November 2003, is among the most important multilateral treaties advancing first generation human rights. The covenant extends a number of protections to the individual, which are particularly relevant to persons with intellectual disabilities or mental illness. In particular, article 9 extends rights to individuals with respect to liberty and security of the person, and prohibits state action which arbitrarily restricts the liberty interests of individuals. As Gostin and Gable note,

> [p]ersons with mental disabilities have frequently invoked these rights and benefited from the protection they provide. For example, the prohibition of cruel, inhuman, and degrading treatment has empowered mentally disabled persons subject to civil commitment to argue for more humane conditions of confinement and treatment. Likewise, the right not to be subject to arbitrary arrest or detention has bolstered efforts to require adequate procedural protections for persons with mental disabilities subject to civil or criminal confinement (2004, 34).

Perhaps the most significant international source of a ‘right to healthcare’ is the *International Covenant on Economic, Social and Cultural Rights* (I.C.E.S.C.R.). Article 12 of this covenant specifies the following:

> 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
>
> 2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

> (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
>
> (b) The improvement of all aspects of environmental and industrial hygiene;
>
> (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
>
> (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness (1976).

The covenant is, of course subject to the limitation that, in order to be effective for citizens domestically, the covenant has to be given expression in the national law of the country whose citizens seek to enforce such rights.

Another significant development with respect to the development of positive rights to healthcare is UN Resolution 46/119, the *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (the "MI Principles"). Although UN Resolutions of themselves are generally incapable of creating legally binding international norms in themselves, they nevertheless have persuasive authority internationally, and serve as recommendations to states with respect to a course of action which should, at a minimum, be taken under advisement (Kindred et al. 1993). In addition, the passage of a Resolution through the General Assembly may be symptomatic of a growing consensus with respect to a particular position. The *MI Principles* specifically recognize the positive right of persons with mental illnesses to treatment. For example, Principle 1.1 specifies that "[a]ll persons have the right to the best available mental health care, which shall be part of the health and social care system" (1991). Although it may be true that Principle 1.1, and the *MI Principles* generally, may be incapable of grounding any positive rights claim against an individual state, it is nevertheless expressive of a growing international recognition of the importance of positive rights, particularly where the rights of the mentally disabled are concerned.

Notwithstanding the existence of a growing body of international law both prohibiting discrimination and limiting state interference with respect to people with disabilities, as well as positive entitlements with respect to the provision of medical services, it is unclear what practical impact these resolutions has in the domestic sphere. In the Canadian context, for example, international treaties only have effect to the extent that they are implemented or incorporated by Parliament: Canadian courts are only entitled to consider international law to the extent that it does not conflict with Canadian law. This is generally unproblematic where negative rights are concerned: both the *Canadian Charter of Rights and Freedoms* as well as provincial human rights statutes and codes repeat (or improve upon) many of the rights guaranteed under international conventions. Furthermore, the Supreme Court of Canada has held that international law should inform *Charter* interpretation. However, as has been mentioned above, Canadian courts have not been overly generous in recognizing positive, social rights. Indeed, as will be discussed below, the Supreme Court of

Canada has thus far been unwilling to interpret the *Charter* as founding a fundamental right to particular medical services.

4. THE CANADIAN EXPERIENCE

The fundamental rights of mental patients, both positive and negative, are enforced in two primary ways within the Canadian context. Legislation and, in some contexts, government action can be challenged in the courts by way of constitutional review; the 'principle' basis of such initiatives is an alleged violation of the Canadian *Charter of Rights and Freedoms* (the "*Charter*"), which enshrines the fundamental rights and freedoms of all Canadian citizens. Pursuant to section 52 of the *Charter*, any law inconsistent with the *Charter*'s provisions is of no force or effect, and can be struck down by the courts. A related, though distinct, method of protecting the rights of mental patients is the avenue of 'judicial review', whereby the decisions of administrative boards or government agencies are subject to review by the courts. Both of these methods of judicial intervention have had important consequences for the advancement of patient rights in Canada.

4.1 The Canadian Charter of Rights and Freedom

As with similar legislation in many other countries, the Canadian *Charter* is a perfect anti-discriminatory document, which should have been the answer to the many forms of discrimination and abuse suffered by mentally ill persons. Section 15(1) of the *Charter* specifically prohibits discrimination on the grounds of "physical or mental disability." Regrettably, this has not been the case, even although four sections of the *Charter* -7, 9, 10 and 15 – are highly relevant to the issue and will be highlighted to exemplify the problems.

It should be readily admitted that the *Charter* has had positive impacts on the plight of the mentally ill in Canada. Based on *Charter* challenges, the legislator has been required to extend procedural fairness to mental health decision making by providing more clarity and transparency in definitions of terms such as mental illness, what constitutes dangerousness or the parameters, and time limitations pertaining to commitment. The *Charter* has motivated the improvement of specialized tribunals like the Review Board system for persons found incompetent to stand trial or not criminally responsible. This has been a significant term of reference for the Consent and Capacity Board in Ontario, and extended the possibilities of appeal and even the right to *habeas corpus* (Consent and Capacity). Nevertheless, mere protection of personal autonomy to make treatment decisions is not enough when facing the larger challenges of social neglect, structural violence, systematic disregard and outright discrimination against the mentally ill. It is in these areas of social functioning where the *Charter* appears to have been ineffective thus far.

a.) The Charter and Negative Rights Section 7 of the *Charter* protects the individual's right to life, liberty and security of the person. This section has been instrumental in advancing the rights of persons with mental disabilities vis-à-vis the justice and corrections systems. In a relatively early case, *R. v. Swain*, the Supreme Court of Canada held that the Crown could not adduce evidence in criminal trials which called into question the sanity of the defendant, as this could have the effect of denying the right of a defendant to control his or her own defense at trial. However, while section 7 has led to favorable outcomes for persons with mental disabilities, it is somewhat limited in scope, even with respect to negative rights; the rights guaranteed can be denied, provided such interference does not violate principles of fundamental justice. Judicial treatment of section XX.1 the *Criminal Code* is instructive in this regard.

Section XX.1 of the *Code* extends certain protections to persons accused of crimes who suffer from mental disabilities; prior to section XX.1, the statutory framework only allowed for a finding of guilty or not guilty. Section XX.1 introduced a third possibility: an accused could be found not criminally responsible (NCR) on account of mental disorder. The scheme set out by Parliament in section XX.1 was challenged in the 1999 case of *Winko v. British Columbia (Forensic Psychiatric Institute)*.[2] The appellant had been found not criminally responsible for a 1983 assault on two pedestrians. According to the scheme of section XX.1, the appellant had been annually assessed by the Review Board, but as recently as 1995 had failed to receive an absolute discharge. He argued that section 672.54 of the *Code*, which grants the Review Board the discretion to discharge absolutely, discharge conditionally, or remand the subject to custody, was unconstitutional for ‘over-breadth’, and for creating a presumption of dangerousness against the subject. The Court upheld the constitutionality of the legislation, finding that the provisions adequately balanced the liberty interest of persons found NCR against the public safety interest, and provided a sufficiently clear framework for legal debate.

Although section 672.54 was upheld in *Winko*, it was successfully challenged in 2004, in the case of *R. v. Demers*. That case concerned the disposition of persons found unfit to stand trial due to mental disorder. Under section XX.1, as it stood in 2004, persons found unfit to stand trial due to mental disorder were ineligible for an absolute discharge; as such, should such an accused suffer from a permanent mental incapacity, he or she would have no hope of ever receiving an absolute discharge, even if it were found that the accused posed no danger to the public. While the Court did not find that the scheme violated the accused’s presumption of innocence, it was found to be overbroad in its application to persons suffering from permanent mental incapacity. As such, the provision was found to be inoperative.

Section 7 of the *Charter* has implications beyond the interaction of persons with mental disabilities and the justice system. Notably, it has been invoked to limit the ambit of the *parens patriae* doctrine, whereby the state assumes custody over minors and persons deemed incapable for the purposes of consenting to medical procedures deemed necessary. In an early *Charter* case, *E. (Mrs.) v. Eve*, the mother of a mentally disabled women applied to the Supreme Court of Prince Edward Island to be appointed committee to her daughter, and authorization to have her daughter undergo sterilization. Her concern was that her daughter would accidentally become pregnant, problematic because as a mother she was not in a position to care for her daughter along with a potential grandchild. The Supreme

Court of Canada found that the application of the *parens patrie* doctrine was limited to the best interests of the subject, not the subject's caregiver(s); while expressing sympathy for the concerns of Mrs. E. for her daughter's wellbeing, the Court emphatically stated that "the procedure should never be authorized for non-therapeutic purposes under the *parens patriae* jurisdiction" (para. 86).

In addition to securing the individual against privations of liberty, the *Charter* enshrines procedural safeguards: Section 8 protects the individual against unreasonable search and seizure; Section 9 protects the individual against arbitrary arrest and detention; Section 10 provides the right to counsel, and imposes an obligation on the state to inform the detained individual of the reason for the arrest or detention. Although these provisions are, as a general rule, rigorously enforced with respect to the individual's interaction with the criminal justice system, the requirements are considerably less stringent with respect to the interaction of persons with mental disabilities and medical practitioners, as is demonstrated by a recent decision of the Superior Court of Ontario, *C.B. v. Sawadsky*. The plaintiff in the case, C.B., had been detained by the police at the request of her daughter, and had been brought to the Toronto Sunnybrook Hospital psychiatric facility for psychiatric evaluation. She claimed that she had not been informed by the assessing doctor of her right to counsel or of the reason for her detention. The doctor, while not specifically recalling having informed her of her right to counsel, or of having her sign a Form 42 document (advising the patient of the doctor's opinion, and advising the patient of her legal rights), the Court found that the doctor had done so. Further, the signing of Form 42 by the patient was determined by the Court to constitute sufficient notice to the patient for the purposes of satisfying the *Charter*:

> Because of the different public purpose, it is difficult to analyze procedural protections in a hospital setting by reference to criminal standards. For the reasons that follow I find that the procedural protections set out in the MHA meet the Charter obligations for a detention under the MHA. The more extensive Charter obligations that require police to inform a detainee for criminal purposes orally of the right to counsel and the opportunity to access free legal advice do not apply (1982, para. 54).

This decision in effect underlines the inherent limitations persons with mental disabilities face with respect to the application of their *Charter* rights; although mental disability is an enumerated ground of discrimination prohibited by the *Charter*, restrictions on the liberty of persons with mental disabilities are subject to a differential standard of scrutiny. While this may be both understandable and necessary, it poses distinct problems for the equal promotion of the human rights of such persons.

Given the prohibition on discrimination on the grounds of mental disability under section 15(1) of the *Charter*, it could justifiably be asked how the distinction in *Sawadsky* can be justified. Unfortunately, the decision in *Sawadsky* is consistent with the case law in this area. In fact, in *Winko*, the Supreme Court also considered a challenge to the constitutionality of section XX.1 of the *Criminal Code* on the basis of section 15(1). The Court found the differential treatment of persons found to be NCR under section XX.1 was not only *not* discriminatory, but that in effect differential treatment was in part necessary as a preliminary to allowing such persons to reintegrate into society:

> an analysis of these provisions of the Criminal Code and their effect upon NCR accused reveals them to be the very antithesis of discrimination and hence not to engage the protections of s. 15(1). Part XX.1 does not reflect the application of presumed group or personal characteristics. Nor does it perpetuate or promote the view that individuals falling under its provisions are less capable or less worthy of respect and recognition. Rather than denying the dignity and worth of the mentally ill offender, Part XX.1 recognizes and enhances them (1985, para. 82).

The Court's logic in *Winko* is interesting, in that it explicitly recognizes that, in some circumstances, differential treatment of certain classes of individuals may in effect be necessary to allow for the successful exercise of civil rights and greater participation in society more generally. At a more theoretical level, there appears to be an implicit acknowledgement that the uniform presumed subject of rights under a liberal, constitutional democracy (that is, the rational, free acting subject) fails to accord to the reality of those with mental disabilities. Unfortunately, this logic (which, it must be recalled, allows the Courts to *restrict* the liberties of persons with intellectual disabilities) has not been deployed to extend positive rights and entitlements to persons with intellectual disabilities.

b) The Charter and Positive Rights The two most promising sections of the *Charter*, upon which several suits have been launched in pursuit of extended social rights, are section 7 (life, liberty and security of the person) and section 15 (discrimination). Although there have been rare instances where the Court has been willing to extend positive entitlements to general classes of individuals under the *Charter*, this has not in effect been extended to grant a right to health care in Canada.[3]

In 2002, the Supreme Court of Canada had the opportunity to address the extent to which both section 7 and section 15 of the *Charter* could ground a positive claim to social services. The case, *Gosselin v. Quebec*, involved a claim that provincial rules governing eligibility for welfare benefits were discriminatory, and constituted a violation of the right to life, liberty and security of the person. The program limited welfare entitlements of persons under thirty to one third the amount allowed persons over thirty; in order to qualify for the full amount available to recipients over the age of thirty, claimants had to participate in approved educational and training programs. In a split decision, the majority of the court held that while there was a distinction in the treatment of those under thirty, it was not discriminatory. More interestingly, with respect to the right to life, liberty, and security of the person, the McClachlin C.J.C. noted the following:

> Even if s. 7 could be read to encompass economic rights, a further hurdle emerges. Section 7 speaks of the right not to be deprived of life, liberty and security of the person, except in accordance with the principles of fundamental justice. Nothing in the jurisprudence thus far suggests that s. 7 places a positive obligation on the state to ensure that each person enjoys life, liberty or security of the person. Rather, s. 7 has been interpreted as restricting the state's ability to deprive people of these. Such a deprivation does not exist in the case at bar.
>
> One day s. 7 may be interpreted to include positive obligations.... The question therefore is not whether s. 7 has ever been – or will ever be – recognized as creating positive rights. Rather, the question is whether the present circumstances warrant a novel application of s. 7 as the basis for a positive state obligation to guarantee adequate living standards.

> I conclude that they do not. With due respect for the views of my colleague Arbour J., I do not believe that there is sufficient evidence in this case to support the proposed interpretation of s. 7. I leave open the possibility that a positive obligation to sustain life, liberty, or security of the person may be made out in special circumstances. However, this is not such a case. The impugned program contained compensatory "workfare" provisions and the evidence of actual hardship is wanting. The frail platform provided by the facts of this case cannot support the weight of a positive state obligation of citizen support (para. 81).

Thus, while not closing the door on a future extension of the applicability of section 7 to social rights claims, it appears clear that, for the present time at least, section 7 cannot be invoked to support a positive claim to government services.

Although the majority rejected such a reading, Justices Arbour and L'Heureux-Dubé both found that the impugned statute violated sections 7 and 15 of the *Charter*. Arbour suggested that the distinction between negative social rights and positive social and economic entitlements ought not to be adhered to. In fact, she posited that the *Charter* should be read, in some contexts, as imposing positive obligations upon the state in discrete circumstances:

> ... I conclude that the s. 7 rights to "life, liberty and security of the person" include a positive dimension. Few would dispute that an advanced modern welfare state like Canada has a positive moral obligation to protect the life, liberty and security of its citizens. There is considerably less agreement, however, as to whether this positive moral obligation translates into a legal one. Some will argue that there are interpretive barriers to the conclusion that s. 7 imposes a positive obligation on the state to offer such basic protection.
>
> In my view these barriers are all less real and substantial than one might assume. This Court has never ruled, nor does the language of the *Charter* itself require, that we must reject any positive claim against the state – as in this case – for the most basic positive protection of life and security. This Court has consistently chosen instead to leave open the possibility of finding certain positive rights to the basic means of subsistence within s. 7. In my view, far from resisting this conclusion, the language and structure of the *Charter* – and of s. 7 in particular – actually compel it (para. 306–307).

Notwithstanding the logic of her argument, this dissent has not decidedly influenced later decisions, nor significantly broadened the nature and scope of rights and freedoms in Canada.

This has been amply demonstrated in a recent unanimous decision, which is particularly relevant with respect to the rights of persons with disabilities. In *Auton v. B.C.*, the Supreme Court of Canada continued with a restrictive interpretation of the *Charter*. The parents of a severely autistic child argued that the B.C. Legislature's refusal to fund a particular form of behavioral therapy constituted a violation of their child's s. 15(1) rights (discrimination) under the *Charter*. Justice McLachlin noted:

> One sympathizes with the petitioners, and with the decisions below ordering the public health system to pay for their therapy. However, the issue before us is not what the public health system should provide, which is a matter for Parliament and the legislature. The issue is rather whether the British Columbia Government's failure to fund these services under the health plan amounted to an unequal and discriminatory denial of benefits under that plan, contrary to s. 15 of the *Charter*. Despite their forceful argument, the petitioners fail to establish that the denial of benefits violated the *Charter* (para. 2).

In its decision, the Court relied upon the analysis against which Arbour argued; that is, claims against the state for the provision of particular services must be rooted in some positive commitment of the state. Put another way, the *Charter* in itself cannot be interpreted as grounding a claim against the state. In the context of *Auton*, the government of British Columbia did not fund the specific services required by the Appellant; under the provincial healthcare legislation, the *Medicare Protection Act* did not purport to extend funding to the services of healthcare practitioners who provided the therapy necessary for the plaintiff. Under the provincial scheme, British Columbia retained discretion with respect to funding of 'non-core' services provided by non-medical practitioners. As a result of the definitions under the scheme, and the province's discretion to fund 'non-core' medical services provided by professionals other than physicians, the Supreme Court was unable to locate any legal obligation on the part of the province to provide the required funding.

According to Sujit Choudhry, *Auton*, as well as the recent decision in *Chaoulli v. Quebec*, mark a new era of Supreme Court adjudication; prior to these decisions, there has been little litigation concerning constitutional aspects of health care before the Court.[4] If *Auton* stands for the proposition that positive rights cannot be enforced absent a specific legislative foundation in Canada, the *Chaoulli* decision stands for the proposition that the government monopoly over health care in Canada potentially violates Canadians' *Charter* rights.[5] In *Chaoulli*, the plaintiff, Dr. Chaoulli, challenged the constitutionality of Quebec's legislation prohibiting the provision of private health insurance in that province. Dr. Chaoulli's patient, on whose behalf he brought the challenge, had suffered various health problems, and had complaints particularly related to waiting times within the public health care system. Although the Court's holding was not unanimous, the majority held that the prohibition on private insurance violated s. 1 of the Quebec *Charter of Human Rights and Freedoms*, which protects the individual's right to life and personal security.

Given the politically charged nature of the decision in *Chaoulli*, the result may be considered provocative. The Court was clearly aware of this dimension to the decision; as Deschamps J., writing for the majority, noted, however,

> The courts have a duty to rise above political debate. They leave it to the legislatures to develop social policy. But when such social policies infringe rights that are protected by the charters, the courts cannot shy away from considering them (para. 89).

In light of both *Auton* and *Chaoulli*, it would appear that the enforcement of a legal right to healthcare, both for persons with mental disabilities, as well as for the general population is not sustainable. Presently, persons with mental disabilities and their advocates should focus on healthcare legislative reforms to ground future claims to the provision of treatment options by the state.

4.2 Judicial Review

Although considerable discretion is granted to different administrative boards in the Canadian context with respect to the involuntary treatment of mental patients, decisions of such boards are nevertheless subject to judicial scrutiny. The recent decision of the Supreme Court of Canada in the case of *Starson v. Swayze* ("*Starson*") is illustrative of the importance of judicial oversight of the decisions of substitute decision makers where persons with intellectual disabilities are deemed incapable of accepting or refusing treatment.

Under the *Health Care Consent Act, 1996*, a person found incapable can be treated without that person's consent. A finding of incapacity involves a determination by a physician that the patient is unable to comprehend both information relevant to treatment, and the consequences of failing to adhere to treatment in question. In *Starson*, the appellant, Professor Starson, had been found incapable and was forced to follow a course of treatment which involved the prescription of medication, including mood stabilizers and neuroleptics. Starson appealed the physician's determination of incapacity to the Ontario Consent and Capacity Board, which upheld the physician's determination. An application for judicial review was brought before the Superior Court of Ontario, which overturned the Board's decision. Both the Court of Appeal for Ontario and the Supreme Court of Ontario upheld the Superior Court's decision.

The principle issue on appeal in *Starson* was whether the trial judge had applied the correct standard of review to the Board's decision, and if so, whether this standard of review was correctly applied. In Canadian administrative law, there is a sliding scale of deference accorded to administrative bodies such as the Consent and Capacity Board; the most deferential standard is patent unreasonableness, whereby the court will not intervene unless the error of the decision maker is obvious on its face. A slightly less deferential standard of review is reasonableness *simpliciter*, whereby the decision arrived at cannot be supported under a somewhat probing examination. Finally, the least deferential standard of review is correctness, whereby the decision of the body must be found to be correct, following a still more exacting examination. The correct standard of review in any given case is arrived at by applying a 'pragmatic and functional' analysis, which is an examination of a number of contextual factors, such as the absence or existence of a right of appeal, the relative expertise of the decision maker, and whether the decision involved a question of fact or law.

In *Starson*, Supreme Court held that the Board's decision was subject to review on a standard of reasonableness. Applying this standard, the Court found that the Board's determination with respect to incapacity was not supported by the evidence; while Starson did not qualify his condition as an illness, he recognized that his brain functioning was not typical. Further, the Board erred in failing to directly ask Starson whether he was aware that his condition would deteriorate without adhering to the proposed course of treatment. Finally, the Board erred in applying the test for capacity; it based its decisions, in part, upon its opinion of the patient's best interest: accordingly, "[t]he Board improperly allowed its own conception of the respondent's best interests to influence its finding of incapacity" (*Starson*, headnote).

The decision is important, insofar as it reinforces the restrictions placed upon the Capacity and Consent Board with respect to the ambit of its jurisdiction. Specifically, the Court emphasized that the Board's mandate was not to determine the best interests of the patient, but to adjudicate the capacity of the person at issue. This approach appreciates that the liberty interest of the patient is at issue, and gives a fuller expression to the *Health Care Consent Act, 1996*, with its emphasis upon patient autonomy and respect for the patient's wishes with respect to treatment.

Although Starson's condition was likely to deteriorate if he did not follow the proposed course of treatment, he objected to the treatment primarily due to the side-effects of the medication. The Board, in imposing its opinion upon Starson, overstepped the bounds set by the legislature; accordingly, *Starson* can be seen as a vindication of the patient's right to elect to follow (or refuse) treatment, notwithstanding the potential consequences.

The availability of judicial review or appeal of a doctor or board's determination regarding capacity is in conformity with international norms respecting the rights of persons with intellectual disabilities, particularly *MI Principle*[6], which mandates in part that "[t]he person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision." Nevertheless, the utility of judicial review, as an avenue for the advancement of the *positive* rights of persons with mental disabilities, is at best limited, considering the fact that administrative bodies are granted circumscribed mandates by the legislatures, and a decision maker's failure to extend a benefit or right not expressly provided for by law could easily be reviewed and overturned on review.

5. RECENT REFORM – THE CASE OF COMMUNITY TREATMENT ORDERS

Even though the Supreme Court has been unwilling to find that the *Charter* guarantees a positive right to government services in the absence of a legislative grounding of such a right, there nevertheless have been positive developments in the method of treatment that is provided by government to persons suffering from a mental disability. Two such examples are Ontario and Saskatchewan, both of which have instituted reforms to their mental health legislation which provide an alternative to institutionalization on the one had, and complete neglect and disavowal on the other. Following the current trend found in a number of jurisdictions, and reflecting the values underlying the *MI Principles*, these provinces now provide for more flexible community invented treatment. Although these developments speak more directly to negative than positive rights, they are indicative of a positive shift in the tenor of Canadian governments' treatment of persons with intellectual disabilities. These initiatives highlight the need for a reconceptualization of the boundary separating positive from negative rights in Canadian jurisprudence.

A community treatment order (CTO) is a course of treatment that a psychiatric patient must adhere to (albeit consensual), but which can be followed outside of an institutionalized context. The use of CTO's for the treatment of psychiatric patients is not a new concept; as Sylvia Bell has noted, "[c]ommunity care gained popularity in the 1960s as developments in psychotropic medication led to the possibility of people with mental illness remaining in the community while receiving treatment" (Bell 2003, 486). Nevertheless, it was not until 1994 that amendments were made to Saskatchewan's mental health legislation that CTO's were available in any Canadian jurisdiction. Ontario followed suit in 2000, with the passage of *Brian's Law*, which amended the *Mental Health Act* to provide for CTO's.

In both Ontario and Saskatchewan, a CTO is only available to patients who have previously been hospitalized for their condition. Notwithstanding this limitation, CTO's are consistent with the *MI Principles*, and as such reflect a commitment to the advancement of the fundamental rights of persons with a mental disability; principle 3 expressly recognizes the right of persons with mental disabilities, to the extent possible, to live in their communities. Although CTO's, much like institutionalization, interfere with the liberty interest of the individual patient, they are far less limiting than coercive hospitalization. Furthermore, in the case of the Ontario reforms, the consent of the patient (or a substitute decision-maker) is required prior to the issuance of a CTO, and such an order cannot be issued unless the patient has been informed of his or her right to retain and instruct counsel. Relative to the institutional model of mandatory treatment, CTO's clearly reflect an advancement of a patient's rights, at least within the framework of negative rights.

However, the success of such treatment depends upon the availability of services in the community to assist the patient subject to a CTO, and the provision of such services is not mandated by the legislation:

> [t]he availability of services is a major issue in both developing and implementing compulsory community treatment legislation (as it is in involuntary in-patient services as well). Obviously, if the resources necessary to meet the conditions of a person's compulsory community plan are not available to the person they could not comply. They would then face being returned to the hospital because of something over which they had no control. Some critics ... argue that no compulsory treatment provisions should be enacted until the full range of mental health service are easily available for everyone; a time that may never come (2006, 20).

Community services which are required for the success of a CTO regime are not restricted to medical treatment in the community; adequate housing, income and training assistance is also necessary to ensure a successful reintegration of the individual into the community, and to counter the social stigma to which persons with mental disabilities are subject. As Bell has noted, when CTO regimes were first introduced,

> [p]olicy makers had not really appreciated the social circumstances in which people with mental illness were likely to find themselves and which led to many people with mental illness being effectively excluded from accessing the necessary material resources for life in the community, a situation not always redressed by anti-discrimination legislation (2003, 486).

In the absence of any guarantees that the services necessary for successful reintegration into the community will be made available to patients under a CTO, it is unclear to what extent these developments will improve their lives.

6. REDRESS

Modern mental health systems do not depend on mental hospitals, but on psychiatric units in general hospitals and on an array of community mental health agencies. These systems need a different level of discourse on human rights that addresses economic discrimination and the disparities in access to health system as well as the systemic, structural violence to which mental patients are subjected to in the community. The human rights discourse has to evolve from over-preoccupation with basic rights to freedom and autonomy to protection of citizen entitlements denied to the mentally ill as a class within the larger social system. The struggle for those who care about them is to gain for them the same rights and entitlements that other citizens enjoy (Farmer 1999).

6.1 From Protection of Basic Rights to Social Neglect

Most legislation dealing with the mentally ill focuses upon the traditional civil or 'first generation' rights, emphasizing the individual's rights to liberty, due process, protection against abuses and the authoritarian imposition of treatment (Laing 1971). While it is very important to keep these protections in place, these regimes are undermined by an anti-institutionalist ideology predicated upon the absolute autonomy of the individual, an ideology which fails to account for the realistic needs. In the majority of countries where deinstitutionalization policies have been implemented, including Canada, mental patients are no longer in mental hospitals, but find themselves thrust into the general community. Most of them do not have access to a bed in any type of hospital. The challenge facing many mental patients is the obverse of what preceded the current model; where systemic abuse and deprivation of freedom constituted the greatest weakness under prior regimes, today's mental patients face structural and systemic neglect. This in turn has had a profound impact on all mental patients, as an unprotected social underclass. Thus, the question, whether mental patients have gained anything may appear to be rhetorical, but looking at the plight of the mentally ill in the mental health ghettos of any large city, or in the prisons, makes the question practical, obligatory and immediate. Furthermore, it is a question that demands answers not only from legislators and policy makers, but from society in general in regard to negative attitudes and lack of understanding of the powerlessness of the mentally ill.

Three levels of social interaction – stigmatizing attitudes, negative rights and powerlessness – are essential to understand the vacuum that exists between official documents and good intentions of the law against discrimination and the realities in the lives of mentally ill persons in modern day society.

6.2 Stigmatizing Attitudes: Perspective, Identity and Reaction

Stigma, prejudice and discrimination have been identified as the reasons for most of the difficulties mental patients face when they are clinically ready to reintegrate into society (Arboleda-Flórez 2003). While stigma and prejudice are attitudes, discrimination is the active denial of entitlements and rights that are ordinarily enjoyed by most citizens. Stigma, prejudice, and discrimination are closely related and tightly interwoven social constructs that are observed across all classes and social groups. Stigma develops within a social matrix of relationships and interactions and has to be understood within a three-dimensional axis (Crocker et al. 1998). These three dimensions have been labeled perspective, identity and reaction.

Mental patients who show visible signs of their conditions because their symptoms or the side effects to medications make them appear strange, who are socially construed as being weak of character or lazy, and those who display threatening behaviors, usually score high on any of these three dimensions. By a process of association and class identity, all mental patients get equally stigmatized. The individual patient, regardless of level of impairment or disability, is lumped together into a class, and class belongingness reinforces the stigma against the individual. This process of lumping everybody together extends to the perception of all mentally ill persons as unpredictable and violent. In addition, the general public's perceptions of the mentally ill are shaped by images in the media or other manifestations of popular culture. The media often depicts patients as dangerous and movies usually follow the popular "psycho-killer" plot, long exploited in the cinematographic industry (Steadman and Cocozza 1978; Byrne 1998). The association between mental illness and violence helps to perpetuate stigmatizing and discriminatory practices against mentally ill persons and is only one of the many negative stereotypes and prejudicial attitudes held by the public about them (Stuart and Arboleda-Flórez 2001).

To the extent that many mental conditions are chronic and incapacitating, mentally ill persons can hardly migrate out of the grip caused by negative social attitudes. The result is social annihilation, a constriction in the lives of the mentally ill that prevents them from full re-integration into their communities and from participating in the social activities of their groups of reference. Fear of stigmatization prevents many persons from seeking opportune treatment or adhering to treatment regimes. Such anxiety at work and fear of job loss keeps many persons within an internal prison of despair until situations become irretrievable.

6.3 Anti-Rights

High levels of stigmatizing attitudes among the general public and even among clinicians may be at the base of what Kelly (2005) calls "structural violence," a pernicious and insidious form of discrimination and abuse, the resolution of which is translated into a deprivation of rights. Mental patients have obtained the anti-right to remain homeless in the streets where they frequently freeze to death on winter nights, are unemployed, or confined to a permanent existence of poverty and charity. In reality mental patients have been disproportionately robbed, mugged, raped, beaten up or murdered in the streets where they sleep for lack of proper accommodations. Should they react violently, many times in self-defense, they are labeled dangerous and sent to prisons. Mental patients have in effect been granted the anti-right to be criminalized and to receive treatment, if any, in prisons and penitentiaries, as opposed to hospitals, where most citizens expect to go if they fall ill (Arboleda-Flórez and Weisstub 1997). The facile manner in which mental patients have been criminalized reinforces the stigmatizing attitudes in society. This has fuelled further fears that they are dangerous and unpredictable, and has led to further calls for expansion of controls via commitment legislation

(Appelbaum 1997; Durham and LaFond 1985). In turn, the harshness of their existence has a negative impact on their illness as biological, psychological and social elements are in close interplay to reinforce etiological factors and to maintain disease status.

6.4 Powerlessness

Unfortunately, mental patients are normally powerless to improve their situation. Poverty, disenfranchisement, and championlessness are all partly to be blamed for this situation.

Mental patients are usually found at the lowest of socio-economic levels. Their socio-economic status is related to the impacts of an illness that attacks before many of them achieve their development potential, thereby truncating their education and reducing their marketability. Many persons who develop mental illness while still young cannot access prompt treatment to help stem the disease and mitigate its effects. Poor knowledge of the nature and presentation of mental conditions, fear of stigma among family members, lack of financial resources, and a health system that does not provide treatment facilities for the young unnecessarily prolongs the period between the appearance of the illness and the first opportunity for treatment. For others who become ill later in life, the illness often leads to unemployment. This leads to a catastrophic loss of income and a rapid fall in the socio-economic scale. Oftentimes, even claiming disability insurance, which has been paid for eventualities of this nature, becomes a nightmare. Insurance companies tend to regard claims suspiciously, curtailing treatment options, and causing the person to incur unnecessary legal costs for experts to redress the injustice.

These problems are compounded by the fact that mental patients rarely have a political voice. Most of them cannot even enter the electoral registries, because they have no address; having no home address, they cannot vote. Lobbying and political activism as exercised by many other patient groups in order to improve their access to better health care, such as facilities and treatment options, are hard to organize among the mentally ill. The families of mental patients are themselves affected. Many live in poverty, so that they too have little political influence. Disenfranchisement and lack of voice render social problems invisible so that the plight of the mentally ill or their families seldom enters the sphere of political debate. This results in the neglect of mental health systems, poor budgetary allocations, inadequate facilities and utter disregard for their social situation. The mentally ill are not just disenfranchised, but totally alienated from the political system.

At its base, the powerlessness of the mentally ill stems from their own mental difficulties, which frequently consume all their energies, compromising their ability to participate in the social arena. Seriously ill mental patients are preoccupied with their delusions and hallucinations; many are too paranoid to even consider trusting others in any form of group action, are disordered because of manic behavior, or are too depressed to even care. Serious mental conditions are incapacitating and disturb the appropriate modulation of affects and behavioral controls. These conditions also alter cognitive processes that are necessary to make sense of complex issues and to express opinions in a coherent fashion, especially if speaking in public, as most political actions require.

In addition to lacking a political voice of their own, the mentally ill also lack political champions. Even when a leader or advocate surfaces and argues for the mentally ill, the motivating force is usually due to outrage stemming from a personal situation for example: oftentimes a close relative has succumbed to mental illness and the champion politician has to face the reality of inadequate services. Unfortunately, fear of negative repercussions in political capital has led politicians to hide the mental illness of their relatives or among themselves. A history of mental illness is a major roadblock to seeking or remaining in public office. Clinicians who feel that they have to confront the social reality of their patients and who have a duty to advocate for them are often seen as self-serving. If they gain political office, they move on to other issues as they do not wish to be typecast as a single-issue politician hammering at something for which there is no political resonance.

7. CONCLUSION

Given the apparent dissonance between internationally recognized rights to adequate healthcare and freedom from discrimination and their strict application in the Canadian context, one might well wonder what advances can be hoped for in the near future. It is important to remain cognizant of the real progress that has been made in recognizing the rights, both positive and negative, of such persons in Canada over the past two decades. The courts, legislatures and Parliament have all, to some extent, contributed to these advances, and recent developments present us with the hope that historical inequities will be increasingly remedied.

Both *Gosselin* and *Auton* failed to establish an unrestricted right to government services (welfare benefits and health care services respectively) in Canada. Nevertheless, given that *Gosselin* reflected a real split at the Supreme Court (in a 5:4 decision), on a new set of facts positive rights might receive greater recognition in Canada. Furthermore, recent human rights adjudication has opened a greater space for the influence of international law in the interpretation of *Charter* rights. As L'Heureux-Dubé noted in *Baker v. Canada (Minister of Immigration)*, "the values reflected in international human rights law may help inform the contextual approach to statutory interpretation and judicial review," even where a given international instrument has not been implemented into Canadian law (*Baker*, para. 70).

Similarly, as noted above, recent legislative developments have assisted in improved recognition of the dignity and worth of persons suffering from mental disabilities. Notably, the recent reforms to Ontario's mental health legislation have brought its system into close alignment with the *MI Principles*, in mandating that, where possible, treatment should take place within the individual's community. However, legislative changes, in the absence of a serious commitment on the part of government to adequately finance community programs to assist persons with mental disabilities to reintegrate into the community, will do little to achieve a desirable outcome.

If Canada is to truly conform to the *MI Principles* and the spirit of the *I.C.E.S.R.*, it will be necessary to secure a better grounding for the establishment of justiciable social rights, either through a more progressive interpretation of the rights granted through the *Charter*, or more likely through specific legislative or regulatory commitments made by governments. Both of these developments are, in turn, heavily dependant upon renewed advocacy efforts by caregivers, lawyers, psychiatrists and politicians. Absent such a commitment, it remains unclear whether the gulf between first and second generation rights can be bridged, and whether the fundamental human rights of mental patients, as recognized by international law, will find expression in Canada.

NOTES

[1] See for example *Gosselin v. Quebec*.

[2] *Winko v. B.C.*; see also *R. v. Lepage*, [1999] 2 S.C.R. 744 and *Bese v. British Columbia (Forensic Psychiatric Institute)*, [1999] 2 S.C.R. 722.

[3] In a recent study, Ran Hirschl noted that "[w]hereas 'negative' rights claimants won 117 cases in the Canadian Supreme Court between 1982 and 1989, claimants for 'positive' and collective rights had only fourteen victories (or a ration of 8:1)" (2000, 1076).

[4] Prof. Choudry's comments were made in the course of his presentation to the International Symposium: The Charter Revolution and the Practice of Medicine, held at the Universite de Montreal in November, 2005.

[5] Potentially, because the Court did not base its ruling upon s. 7 of the Canadian *Charter*. The Quebec *Charter* is broader in scope than the Canadian *Charter*, and as such, the holding may not have an overly dramatic effect in the Canada-wide context.

[6] *MI Principles*, the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, act as guiding standards when interpreting treaties as they provide an international standard of the rights for the mentally ill (Gostin and Gables 2004).

REFERENCES

Appelbaum, P. (1997) Almost a revolution: An international perspective on the law of involuntary commitment. *Journal of the American Academy Psychiatry and the Law,* 25: 135–147.

Arbour, L. Statement by Ms. Louise Arbour, High Commissioner for Human Rights to the Open-Ended Working Group established by the Commission on Human Rights to consider options regarding the elaboration of an optional protocol to the International Covenant on Economic, Social and Cultural Rights, available online at http://www.unhchr.ch/huricane/huricane.nsf/0/ECAE2629449C1EB-CC1256F8C0035047D?opendocument.

Arboleda-Flórez, J. (2003) Considerations on the stigma of mental illness. *Canadian Journal of Psychiatry*, 48: 645–650.

Arboleda-Flórez, J. (2005) Forensic psychiatry: Two masters, one ethics. *Die Psychiatrie* 2: 153–157.

Arboleda-Flórez, J., Weisstub, D.N. (1997) Epidemiological research with vulnerable populations. *Acta Psychiatrica Belgica*, 97: 125–165.

Bell, S. (2003) *Rights Issues in Compulsory Community Treatment in Involuntary Detention and Therapeutic Jurisprudence: International Perspectives on Civil Commitment*. Burlington: Ashgate.

Brant, S. (2005) *Stultifera Navis, 1497* Retrieved December 14, 2005 from http://www.spamula.net/blog/-archives/000429.html .

Byrne, P. (1998). Fall and rise of the movie 'psycho-killer'. *Psychiatric Bulletin*, 22: 174–176.

Crocker, J., Major, B., Steele, C. (1998) Social stigma. In D. Gilbert, S. Fiske, G. Lindzey (eds.) *Handbook of Social Psychology* (4th ed., vol. 2). Boston: McGraw-Hill.

Durham, M., LaFond, J. (1985) The empirical consequences and policy implications of broadening the statutory criteria for civil commitment. *Yale Law and Policy Review*, 3: 395–446.

Dörner, K. (1974) *Ciudadanos y locos* (trans. Taurus). Frankfurt: Bürger und Irre.

Farmer, P. (1999) Pathologies of power: Rethinking health and human rights. *American Journal of Public Health*, 89(10): 1486–1496.

Foucault, M. (1988) *Madness and Civilization* (trans. R. Howard). New York: Vintage Books.

Gracia, D., Lázaro, J. (1992) Historia de la psiquiatria. In J. Ayuso Gutierrez, L. Carulla (eds.) *Manual de Psiquiatria.* Bototá: Interamericana-McGraw-Hill.

Gostin, L.O., Gable, L. (2004) The human rights of persons with mental disabilities: A global perspective on the application of human rights principles to mental health. *Maryland Law Review,* 20, 63.

Häfner, H. (1991) The concept of mental illness. In A. Seva (ed.), *The European Handbook of Psychiatry and Mental Health.* Barcelona: Editorial Anthropos.

Hirschl, R. (2000) 'Negative' rights vs. 'positive' entitlements: A comparative study of judicial interpretations of rights in an emerging neo-liberal economic order. *Human Rights Quarterly*, 22, 1060.

Kelly, B.D. (2005) Structural violence and schizophrenia. *Social Science and Medicine*, 61: 724–730.

Kindred, H.M. et al. (1993) *International Law: Chiefly as Interpreted and Applied in Canada* (5th ed.). Toronto: Emond Montgomery.

Kinney, E.D. (2001) The international human right to health: What does this mean for our nation and world? *Indiana Law Review*, 34:1457–1475.

Konrad, N. (2002) Prisons as new hospitals. *Current Opinion Psychiatry*, 15: 583–587.

Laing, R. (1971) *Psychiatry and Anti-Psychiatry.* London: Tavistock Publications.

Ontario Consent and Capacity Legislation. (1998) Aurora: Canada Law Book Inc.

Pinel, P. (1988) Tratado Medico-filosófico de la enajenacion mental o mania (1801). Madrid: Editorial Nueva.

Steadman, H., Cocozza, J. (1978) Selective reporting and the public misconceptions of the criminally insane. *Publ. Opinion Quarterly,* 41: 523–533.

Stuart, H., Arboleda-Flórez, J. (2001) Community attitudes toward people with schizophrenia. *Canadian Jounal of Psychiatry*, 46(3): 55–61.

Vives, J.L. (1980) *De Anima – Antologia de Textos de Juan Luis Vives* (trans. F. Tortosa). Vanencia: Universitat de Valencia.

Weisstub, D. (1985) Le droit et la psychiatrie dans leur problématique commune. *McGill Law Journal*, 30: 221–265.

JURISPRUDENCE

Baker v. Canada (Minister of Immigration), [1999] 2 S.C.R. 817.

Bese v. British Columbia (Forensic Psychiatric Institute), [1999] 2 S.C.R. 722.

C.B. v. Sawadsky, [2005] O.J., No. 3682.

Chaoulli v. Quebec (Attorney General), [2005] 1 S.C.R. 791.

E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388.

Gosselin v. Quebec (Attorney General), [2002] 4 S.C.R. 429.

R. v. Demers, [2004] 2 S.C.R. 489.

R. v. Lepage, [1999] 2 S.C.R. 744.

Starson v. Swayze, [2003] 1 S.C.R. 722.

R. v. Swain, [1991] 1 S.C.R. 933.

Winko v. B.C. (Forensic Psychiatric Institute), [1999] 2 S.C.R. 625.

LEGISLATION

Canadian Charter of Rights and Freedoms, s. 7, Part I of the *Constitution Act, 1982,* being Schedule B to the *Canada Act 1982 (U.K.), 1982, c. 11.*

Health Care Consent Act, 1996, S.O. 1996, c. 2, Schedule A.

Mental Health Act, R.S.O. 1990, ch. M-7

Mental Health Act, R.S.S. 1978, c. M-13

Criminal Code of Canada, R.S. 1985 c. C-46

International Covenant on Civil and Political Rights, 19 December 1966, 9999 U.N.T.S. 171, arts. 9–14, Can T.S. 1976 No. 47, 6 I.L.M. 368 (entered into force March 1976, accession by Canada 19 May 1976)

International Covenant on Economic, Social and Cultural Rights, 16 December 1966, 2200A U.N.T.S.

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Healthcare, GA Res. 46/119, UN GAOR, 46th Sess., (1991) 188.

Loi sur les aliénés n° 7443 du 30 juin, 1838, J.O., 6 July 1838.

PART V

INDIVIDUAL INTEGRITY, RESEARCH ETHICS AND HUMAN RIGHTS

JUDITH KISSELL

CHAPTER 22
THE “VULNERABILITY” QUAGMIRE IN INTERNATIONAL RESEARCH

> A religiously inspired principle of healing might be stated this way: the greater the vulnerability of a human being, the greater the protection we ought to afford. “The first shall be the last, and the last first.” This is a derivation from the religious expansion of the principle of justice. In this view, the impediments to equality of respect, in an ideal community, ought to be removed by the members of that community.
>
> *Helping and Healing*, Edmund D. Pellegrino and David C. Thomasma

INTRODUCTION

Every once in a while there is a wake-up call. The question of justice in healthcare, and particularly in reference to research ethics, compels such an alert. There are few healthcare justice issues in the world that require such careful examination as those that surround the conduct of clinical trials in the developing nations of the southern hemisphere and the underdeveloped nations of Eastern and Central Europe and the former USSR. These justice questions are both national and international, because we in the Western world stand to benefit – exclusively for the most part – from such research. What often remains unrecognized is who pays the price for our obtaining this benefit. While it appears easy to convince the public that those who gain from foetal tissue research are morally connected to the ways of acquiring that tissue – perhaps even to an abortion – we are less likely to concede to the justice version of that argument. Those who benefit from research conducted on the poor and vulnerable are also morally connected to how those benefits are attained. Indeed, researchers and their sponsors are responsible. But so are we all.

Every once in a while there is indeed a wake-up call. Such was the publicity that surrounded the story of the syphilis experiments conducted at Tuskegee and finally publicised in 1972. This story resulted in widespread changes in public policy in the United States and an alert to nations around the world about how research was being conducted and how research subjects were being treated. “Tuskegee” became a code word for the exploitation of persons who were poor and helpless for the benefit of those who would not put up with such treatment. And it was used again about another set of important studies. When Dr. Marcia Angell, executive editor of the *New England Journal of Medicine*, called the short course AZT trials “not...very far from Tuskegee,” (Angell, 1997, 847) everyone knew what she meant.

If the ethical importance of a case is measured by the fruitfulness of the reflection that it stimulates, the wealth of issues that it raises and the understanding

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 331–340.

that it produces, then one of the most significant cases of contemporary research and research ethics has been that of the short course AZT studies. This case alerted us to how we should be thinking about research conducted internationally, particularly in less fortunate nations. One of the most important consequences of the AZT controversy has been the statement, restatement, commentary and further thinking surrounding the issue of whether the medical standards of the country in question dictate a different and quite possibly attenuated responsibility toward the subjects of clinical research. A further important consequence of the debate, though one that has garnered too little attention, is the idea that the motivation behind research can define the exploitation of the vulnerable. The fact that the AZT trials were conducted by agencies bent on helping the population whom the subjects represented earned only a little notice. Few if any comparisons were made to distinguish between the AZT research and that conducted on medical products by pharmaceutical companies. The AZT research was motivated by the very vulnerability of the poor. Pharmaceutical industry research too is motivated by the vulnerability of the poor, but in a different way.

This paper explores the meaning of vulnerability in relation to internationally conducted medical research. Taking as a starting point once again the AZT trials, it looks at how that paradigm case embodies the issues central to research conducted in developing countries. But this time it throws a particular light on the difference between research conducted by profit and not-for-profit entities. It looks at how the commercialisation of medicine by the pharmaceutical industry gives a new twist to the definitions of vulnerability put forth by national and international regulatory documents, even to the point of creating a new class of vulnerable subjects. Finally, it examines the incommensurability of medicine and business.

The AZT Short Course Trial as Paradigm The nature of the AZT trials is only tangentially related to the particular issue I raise here, but it is important, nevertheless, to understand what the trials were about. These trials present a paradigm that brought together most of the ethics issues surrounding research among the poor and defenceless. They were designed to test for alternative cheaper methods of preventing maternal-foetal transmission of HIV. Begun in 1995, the trials were conducted in Thailand, Uganda, Ethiopia, Tanzania, South Africa, the Dominican Republic and the Ivory Coast. They were sponsored by the United States Centres for Disease Control (CDC) and National Institutes of Health (NIH). The case brought into high visibility issues fundamental to respect for human subjects in this age of commercialised medicine, in a world sharply divided by wealth and poverty: exploitation of vulnerable populations from developing and under-developed nations; the role of poverty in healthcare disparities; what is owed to the countries whose subjects participate in trials for drugs they cannot afford; and the contrast between the profit-driven activities of pharmaceutical companies and the public health efforts of governmental, NGO and other aid organisations. Criticism of the AZT short course trials was a call for serious pondering on the apparent double standard of research ethics that seemed to be determined by the location of the research and by the economic status of its subjects. At particular issue was the use of placebos in the study's control arm, a practice prohibited in developed countries where stricter controls on protection of human subjects exist. However, like many problems that at first blush appear simple and straightforward – right or wrong – the ongoing discussion of the AZT trials has shown how convoluted and difficult to resolve are the social and economic problems in developing/underdeveloped nations, especially as they relate to health. The issues, discussions and reflection sparked by these controversial studies have been far-reaching and complex. National and international bodies have attempted, with varying degrees of success, to address the problems the trials raised. What *has* been successful is the new global attention and rich discussion that now attends research carried out in the developing world by wealthier nations.

The AZT trials were designed by the CDC and NIH with the cooperation of other international AIDS organizations. They were focused on meeting the needs of developing nations where HIV and AIDS had reached crisis proportions but where countries were hampered by their economic conditions from providing adequate treatment. The short course was designed to impede the maternal-fetal transmission of HIV at a cost manageable for nations that could not afford the more expensive standard treatment. The standard ACTG Protocol 076, used in the West, was considered too complex and prohibitively high-priced for use in many parts of the world. In the interests of expediting the development of a treatment, and given the crisis situation of the AIDS epidemic, a placebo control arm was included in the trial design (in the Thai study, for instance, half the women were in each study arm (Levine, 1998). The study was discontinued in 1997 owing to the clear evidence of the success of the short course, although even its significantly lower cost proved unaffordable for the countries the trial was meant to help.

It was at this point that Angell, citing a "retreat from ethical principles," enkindled the highly controversial, but rich, discussion on the apparent double standard of ethics as it was applied by the arrogant West to poorer countries.

Discussion about exploitation of vulnerable populations, the role of poverty in healthcare disparities; what is owed to the countries whose subjects participate in trials for drugs they cannot afford and other related issues has continued. While most of these issues have been visited and re-visited in articles and books in the last several years, little attention has been given to the distinction between research conducted by governmental agencies, such as the United States' CDC and NIH, other governmental aid organisations from the United Nations, NGO's, etc., versus those conducted by pharmaceutical companies.

The National Bioethics Advisory Commission (NBAC) report, *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries* published in 2001, addressed the problem of pharmaceutical companies briefly: "Some observers believe that market forces have pressured private organisations to become more efficient in the conduct of research, which may – absent vigilance – compromise the protection of research participants" (NBAC, 2001, i). More obliquely, the report points out: "The background fear is a breach of distributive justice, since products that disadvantaged populations bear the burden of testing are likely to be marketed in affluent countries and be unavailable to populations of poor countries that served as testing sites" (NBAC, 2001 A–7).The Council for

International Organizations of Medical Sciences (CIOMS) *International Ethical Guidelines for Biomedical Research Involving Human Subjects,* revised in 2002, goes into more detail about the responsibilities of pharmaceutical companies.

But a thoroughgoing grasp of the differences in standards that *should* exist between for-profit companies is clearly lacking in both the international and American regulatory documents. In the paradigm AZT case, the CDC/NIH had been active in helping the host nations on a variety of fronts in combating HIV/AIDS before initiating the controversial study. Researchers were confronted by the seriousness of the AIDS epidemic in Africa and Asia, the need to respond quickly to the problem and the possibly very important benefit to countless others in the host and other poor countries, balanced against the risk to the fetuses receiving a placebo.

Unlike the AZT trial that aimed at developing a treatment that would cost less than 10% of the standard procedure, pharmaceutical company trials aim at increasing profit to the company and its shareholders. Unlike the agencies that conducted the AZT trials, pharmaceutical companies do not respond to epidemic or crisis situations in poor countries but rather to the market. Not only are the poor likely to be excluded from the advantages of drugs the companies develop, but the poor, and they alone – susceptible to the risks of the trials – are *disadvantaged* by its development – a kind of reverse Rawlsian phenomenon. One of the neglected lessons from the AZT paradigm is that we need to look differently at public health efforts from the way we regard the metamorphosis of healthcare into a commercial enterprise. Key to understanding this difference is a grasp of vulnerability and how commercialisation of health-related research has created a new class of vulnerable persons. Two cases are particularly illustrative of the problem of the new vulnerability created by the commercialisation of medicine and of how pharmaceutical companies reason about the problem.

The "'No Treatment' is the Standard'" Surfactant Case The first case was reported in the NBAC's Ethical and Policy Issues in International Research. A US biotechnology company application for approval of a study, geared to the US market, of a new surfactant drug for treating infants with the possibly fatal Respiratory Distress Syndrome (RDS). The study design – clearly disapproved of by the NBAC and rejected by the FDA – included two control groups of premature infants. The first group, in Latin America, would be given placebos rather than the already approved surfactant drug. The second, in Europe, would be treated with an accepted surfactant drug rather than the placebo. European, as well as US regulations forbid the use of a placebo where a satisfactory treatment exists. As justification for the difference in treatment, the company contended " ... that because infants in Latin America with RDS who do not have access to established drugs would not be left worse off [emphasis added] by placebo treatment, the proposed study is ethically justifiable in the hospitals where surfactant drugs are not available" (NBAC, 2001, 25 Exhibit 2.3). The question of how one measures treatment standards in healthcare-poor nations became a major issue in the discussions stimulated by the AZT short course trials. How, the question was asked, is giving a placebo different from the situation that ordinarily holds in poor countries in which children are given nothing at all for the medical condition in question? If HIV positive pregnant women in certain countries generally receive *no* treatment to prevent the transmission of the virus to their children, then how is using a placebo arm in the AZT short course study ethically questionable? If Latin American women cannot afford a surfactant drug for their newborns, why is giving a placebo to some of them wrong?

The researchers of the surfactant study saw their ethical obligation as, "not to leave the infants worse off" – a particularly chilling statement of responsibility from power-wielding, medical professionals from wealthy nations, who stand to profit greatly, describing how they should treat vulnerable, newborn infants from poor families living in poor nations, who are, owing to these researchers, likely doomed to die.

The ethical and philosophical issue is precisely this matter of "who are, *owing to these researchers,* likely doomed to die" or left to suffer, having fulfilled their required role. This is the allegation that the surfactant researchers hope to resist, but an analysis of responsibility suggests that the charge of causing death is appropriate. The determination of human causation is uniquely aimed at attributing first, responsibility and then accountability, i.e., determination of blameworthiness or the lack thereof, for certain results, especially harms. *Allowing harm to occur,* as opposed to actively *causing harm,* is notoriously difficult to describe. But that allowing can be culpable is beyond controversy. And culpable "allowing harm to occur" by the surfactant researchers is precisely how we might describe what would happen in the Latin American version of the study with its placebo control arm.

True, if the biotech company never appeared on the scene, and given the normal lack of access to the drug, harm would occur – or would be *allowed* to occur – to these subjects. True too, we could attribute this harm to conditions of poverty, lack of access to healthcare and/or policy decisions made by the relevant governments. But it is simply *not* true that once the research team enters the picture – once they intervene in the events that lead to harm – they occupy the same moral space that they would have before their arrival. In an ethically relevant sense, the infants would have been no worse off had there been no study. But at the initiative of the company, there *would be* a study and a situation over which the researchers then have control. In fact, one must suppose that the European control arm of the surfactant study was designed precisely *not to allow* harm to its subjects. The researchers cannot deny their agency in Latin America where the risk of harm is *allowed,* but accept it in Europe, where the trial would be designed to *avoid* harm. The one trial is designed to protect the "researchees" while the other is designed so as to allow the risk of harm. The surfactant study *allows* harm, or the risk of harm, to the infants when the researchers could prevent it. They thereby contribute to the harm.

While on the surface the cases may seem the same, a comparison with the AZT study clarifies the analysis of the surfactant study and the rationale offered by the biotech company as their ethical justification. Unlike the AZT trial, the surfactant study was not a response to epidemic or crisis situation. Rather, it was a response to the market possibilities present in wealthy industrial nations. Neither was quick response an issue, for in the developed world an acceptable treatment already exists. Furthermore, it is questionable that the surfactant being tested would be proved to be superior to that already on the market. This case is not only reflective of the reasoning that one pharmaceutical company did – and others might – bring to bear on an ethical problem, but it also throws light on a more recent case described in a *New York Times* article, "Companies Facing Ethical Issues as Drugs are Tested Overseas."

The "It's not Our Business" Ranolazine Case The second case raises a similar issue and one widely debated after the AZT trial discussions. Only recently, the New York Times raised the issue of the obligation that a California pharmaceutical company owes to subjects in Russia who were subjects in a trial for a new drug, Ranolazine, designed to ameliorate angina attacks Kolata, 2004). The article raises important questions: When companies go to poor countries whose citizens cannot afford the drug they are testing, what does the company owe to the subjects who participated in the trial or to the citizens of the country of those subjects? When researchers finish a trial and depart to market their drug in the more prosperous West, are they abandoning the research subjects? Do business considerations override the ethical obligations that forbid abandonment? Or do pharmaceutical companies so insulate themselves from the demands of clinical ethics that abandonment or fidelity to these subjects is not even a consideration? An argument similar to the one about surfactant can be made here about company responsibility. The companies initiate their accountability for the subjects who are also patients, particularly by using the patients' own doctors to recruit them and to act as clinical researchers. If the company had never intervened in the patient's life, they cannot be held guilty of abandoning them or of encouraging their physician participants to do so. But once the company intervenes, they become responsible and they bear liability for the abandonment.

The Ranolazine case lacks the profusion of issues contained in the AZT case, but it suffices to show that the question of responsibility toward the poor has neither been resolved nor gone away. The subjects in this study suffered from frequent debilitating and painful attacks of angina. "Terrifying, crushing chest pains can come on without warning and often persist despite bypass surgery, angioplasty and medications. Ranazoline can make a difference." So the question is whether the drug company, CV Therapeutics in this case, has any responsibility to these patients once the trial is over. None of the subjects can likely afford the medication on her/his own once the trial is concluded. While the trial will result in reduced suffering for those in the West who can afford the drug, the subjects who jeopardized their health to test the drug go back to terror and pain.

Still, arguments are offered in the hope of downplaying the moral connection between those who bear the risks of this research and those who bask in its benefits. Covance and Russian Clinical Trials contract drug trials to be conducted outside the United States. Asserting that they are not responsible for what happens when drug trials are concluded, Dr. Alan Wood of Covance states; "What our clients choose to do is not our affair." And the drug company contractor – clients apparently feel no responsibility either.

Ethicists and drug companies alike point to their accountability to stockholders as reasons for not abiding by the CIOMS protections of vulnerable populations. "Compassionate use" provision of drugs to poor countries demands setting up distribution systems and training of doctors for the administration and follow up of patients. Such an infrastructure detracts from the profits the companies owe to their stockholders, they argue. Without blinking an eye, the companies defend their use of poor countries in which to do their research precisely because, particularly in Eastern and Central Europe and Russia, the medical system infrastructure already exists with well-trained competent healthcare professionals. "It's not that we are lacking compassion," explains Carl Feldbaum, president of the Biotechnology Industry Organization, "but the economics are tough." This from and industry that had $530 billion dollars worth of sales in 2003 (Herper, 2004) and whose average annual sales since the mid-1990s, has increased at least 10 percent (Washington Times, 2004). This attitude toward research subjects creates a whole new category of vulnerability among research subjects.

TRADITIONAL CONCEPTIONS OF "VULNERABILITY"

Vulnerability as an Historical Concept The concept of vulnerability is used to describe potential research subjects who, for a variety of reasons, have the potential to be abused. The concept has been developed by reviewing the recent history of research abuses: those conducted in the Nazi concentration camps; the Tuskegee study on syphilis; studies done in schools for retarded children at the Willowbrook and Fernald Schools; research conducted in prisons and other institutions and even that done by the United States government on unsuspecting subjects in the military as well as in civilian hospitals. Historically, the vulnerable included those who are administratively convenient owing to their presence in institutions; those who are unable to decide for themselves owing to lack of competence, education or information; the poor and children. "Vulnerable subjects" as defined and described in *Title 45 Code of Federal Regulations, Part 46 Protection of Human Subjects,* include children, prisoners, pregnant women, handicapped or mentally disabled persons, economically or educationally disadvantaged persons, and most recently, foetuses. A vulnerable person is identified in this document as one who is susceptible "to coercion or undue influence." Precise and careful attention is given in the document to each of these categories of persons and specific protections laid out as requirements for including them in research.

While the CIOMS document recognizes the susceptibility of this group, it represents as well a new stage in the history of vulnerability – the defencelessness of those who suffer from systemic poverty and political powerlessness in the face of the commercialisation of medicine by the Western world. The broader definition and description of vulnerability contained in the CIOMS document reflects the new historical reality of for-profit companies, encouraged by numerous contemporary events, to treat healthcare and the development of medical products as a new and lucrative kind of commercial good. CIOMS addresses the issue of “vulnerability – of individuals, groups, communities and populations ...” used in “low-resource countries” by those that are well off. The document defines the vulnerable as those who have a “substantial [or relative or absolute] incapacity to protect [their] own interests owing to such impediments as lack of ... alternative means of obtaining medical care of other expensive necessities ....” According to the document, this incapacity may be related to insufficient power, education and resources, as well as the inability to protect their own interests.

It appears that it is precisely the vulnerability of potential research subjects that motivates commercial researchers to set up research facilities in the developing and under-developed world. By moving into Africa, South America, Southeast Asia and Eastern and Central Europe, companies improve their profits because their research and development costs are greatly minimized. Companies have less to worry about in terms of violating human subjects protections, since these poor countries have fewer regulations and less oversight to protect their subjects. Graft and corruption often cause authorities in such countries to side with business interests in promoting research, regardless of the cost to their own citizens. In the developing nations, *per capita* costs for healthcare are minimal, so that the treatment and medication that can be obtained from participating in research may be the subjects’ only access to these necessities. That the poor and disenfranchised become easy targets of the wealthy and powerful commercial enterprises is the motivation behind CIOMS’ concern with vulnerability.

The Non-commensurability of Medicine and Business Research Interests Ethicists, apparently, find themselves in a quandary about how to weigh the welfare of the poor and vulnerable against the rights of the wealthy and powerful. While, for instance, the CIOMS Guidelines have furthered our historical understanding of vulnerability, their language in relationship to possible exploitation by commercial interests indicates a revealing naiveté about the companies against whom they claim to protect the poor. “Paternalism on the part of the richer countries towards poorer countries should be avoided,” [emphasis added] the document proclaims. The reference to “paternalism” calls forth yet a further, earlier paradigm about the ethics of medicine that focused healthcare professionals on treating patients as self-determining persons. But the reference to “paternalism” does something more disturbing – it also reflects a distressing ambivalence about business and commercialism. This term brings to the ethicist’s mind the kindly, fatherly (literally) but overbearing physician from earlier times who made decisions for his patients and withheld information from them. He did so presumably from his concern over their well being, but also out of his conviction that he knew better than they what was good for them. “Paternalism,” however, is hardly the image that adequately characterises the pharmaceutical company exhorted by the CIOMS documents. Despite this slip into naiveté, the CIOMS *Guidelines* speak unambiguously about the responsibility of researchers to make available to their subjects the fruits of their research (CIOMS, 2002). Ethicists who address these issues are more reticent. They argue instead about the ambiguity of the responsibility of these companies toward research subjects while showing little uncertainty about the company's apparently overriding obligation to stockholders (Kolata, 2004). Lawrence Gostin, director of Georgetown's Centre for Law and the Public's Health, says, "[Parachute research, in which companies that do their studies and then leave] raises the question of what ethical obligation, *if any* , there might be to give back and make sure there is access to the drug after the trials are over."[7] [emphasis added] Ruth Faden, in commenting on what is owed to research subjects says, "We seem to hit a wall of moral unease. In the end, I'm not sure exactly where we ought to end up" (Kolata, 2004). Gostin's and Faden's ambiguity about company responsibilities is stunning, given that the governing regulatory documents on research ethics stress the injustice of expecting some – especially vulnerable – populations to bear the risks of research while others (the West) reap the benefits.

The reasoning that attempts to justify the rendering vulnerable of the world's poorest in order to benefit the world's richest takes various turns. While we seldom have access into the reasoning of pharmaceutical companies vis-à-vis conducting research among the vulnerable, one argument gives further insight into the notion of vulnerability itself. Eugene Braunwald from Harvard University Medical School suggests that the reluctance of people in the United States to participate in research explains, if not justifies, the turn to poor countries. But his argument accounts instead for a further characterization of the *non-vulnerable* person. The repetition and the widespread *reporting* of repeated abuses in this country have made Americans justifiably wary of becoming research subjects. One need only think about the reported scandals at the Fred Hutchinson Cancer Centre in Seattle (Wilson and Heath, 2001), the death of a healthy research subject at Johns Hopkins Hospital in Baltimore (Altman, 2001) and of Jessie Gelsinger during a gene transfer trial (Stolberg, 2000), to understand the reluctance of Americans to participate in these trials. Being informed about research abuses along with access to healthcare that is relatively plentiful in the West, reduce vulnerability.

At the heart of the dilemma about research ethics is an unrecognized, if not purposely ignored, incommensurability between healthcare and business. But to claim simply that health-related and business interests differ is to misrepresent the case. The problem is not that such interests fail to coincide – it is rather to be found in the very nature of healthcare itself. For healthcare is *essentially* a moral enterprise while business merely *has* – or should have – an ethic.

Healthcare is essentially – that is, at its very heart – what *should* be done by one party for the well being of another human being. The fiduciary relationship that characterizes the physician-patient relationship is the obligation by the healthcare professional to serve another person even at some cost to oneself. It entails the efforts of a practice to help the Other to flourish as a human being. Health is an end in itself insofar as it is integral to being human and to having the capability to live a full human life. Healthcare practice holds in its hands the ability to assist persons to fulfil their humanity. It is this intimacy between health and humanity that make healthcare an essentially moral endeavour.

Business and the market, alternatively, are essentially about the exchange of goods that are the *means* to the end of human fulfilment. The justifiable realms of the market place are those goods for which the preferences of the individual can be expressed in market value. Business seeks to take healthcare out of its essential context and to subjugate it along with its physician practitioners – to the standards of business. To seek to determine the responsibilities of the health-related enterprise within the confines of the commercialization of pharmaceutical trials is a category mistake (Pellegrino, 1999). Consider the comment of chief executive of CV Therapeutics, Dr. Louis G. Lang: "CV Therapeutics, he noted, is a business, not a charity."[7] This oft-heard bromide not only totally misrepresents what is at stake but speaks to the heart of the incommensurability of business and the healthcare ethic. Moreover, it speaks to the heart of the problem that arises when business lacks the ethics that it *should* have. What is at stake here is not charity at all, but rather justice – the issues of distributing risks and benefits, of giving research subjects their due, of not exploiting the susceptible.

CONCLUSION

The AZT study provides a seemingly inexhaustible source of moral, social, policy and clinical reflection. The surfactant and Ranolazine cases, however, seem to indicate that pharmaceutical companies will continue to allow harm to occur to patients who were vulnerable to begin with, from whom they've drained usefulness and for whom economic arguments allow them to disclaim responsibility. Business creates a new kind of vulnerability, not because it returns to the old errors of clinical medicine that failed to treat patients and subjects as autonomous, self-determining persons, as the CIOMS *Guidelines* would suggest; and not because the obligations of companies either outweigh the meagre prerogatives of individuals; or because the obligations of such companies is in some way obscure, as Gostin and Faden suggest. Rather, when business enters healthcare it creates vulnerability because the notion of profiting from the mere *means* to reach human fulfilment is incommensurable with health as integral to human flourishing and in this strange struggle, money and power seem too often to win.

REFERENCES

Altman, L.K. (2001) Volunteer in asthma study dies after inhaling drug, *New York Times,* June 15.

Angell, M. (1997) The ethics of clinical research in the third world, *New England Journal of Medicine,* 337, 847–50.

Council for International Organizations of Medical Sciences (2002) *International Ethical Guidelines for Biomedical Research Involving Human Subjects,* Geneva. Available online in http://www.cioms.ch/frame_guidelines_nov_2002.htm

Herper, M. (2004) The world's best-selling drugs, *Forbes*, March 16.

Kolata, G. (2004) Companies facing ethical issue as drugs are tested overseas, *New York Times,* March 5, 2004.

Levine, R.J. (1998) Best Proven Therapeutic Method" Standard in Clinical Trials in Technologically Developing Countries, *Ethics and Human Research*, 20, No. 1. pp. 5-9.

Pellegrino, E.D. (1999). The commodification of medical and health care: The moral consequences of a paradigm shift from a professional to a market ethic. *Journal of Medical Philosophy,* 24, 243-266.

Stolberg, S.G. (2000) Gene therapy ordered halted at university, *New York Times,* Jan. 22.

North Americans boost drug company sales (2004) *Washington Times*, March 16.

United States National Bioethics Advisory Commission (2001) *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries.*

Wilson, D. and Heath, D. (2001) Uninformed consent, *Seattle Times,* March 11.

GEORGE F. TOMOSSY

CHAPTER 23
HUMAN RIGHTS, HEALTH CARE AND BIOMEDICAL INNOVATION: CONFRONTING THE RESEARCH IMPERATIVE

Medicine has continued to evolve from its observational roots in the Hippocratic tradition to become increasingly reliant on experimentation[1] This has occurred in response to a number of forces, including the amalgamation of bedside, hospital and laboratory medicine; the growing professionalization of medical training; and the grouping of patients into large easily accessible numbers concomitant with the rise of hospitals (Bynum 1988: 36–40; Rothman 1991: 24; Lederer 1995: 6–7). The increasing dominance of medical academia by investigators was aptly noted by Henry Beecher some forty years ago (1966), with the work of post-war "therapeutic reformers" throughout the twentieth century having ensured that "physicians' therapeutic practices are governed by science and not by the 'idols of the marketplace' or the vagaries of clinical opinion" (Marks 1997: 230).

In the modern era of health care, the relevance of biomedical research has never been stronger. Aside from the direct benefits of new medicines, increased funding for health research is strongly promoted on the grounds that it will lead to public health care cost-savings and economic returns attributable to longer and healthier human lives (Funding First 2002; Rosenberg 2002). This link has also been made in a global context, where it has been asserted that resources committed by developed nations to the health needs of developing countries, including in terms of relevant health research, would be an investment that would be repaid "many times over" (WHO Commission for Macroeconomics and Health 2001: 1). With such powerful pressures to cultivate and harvest the rewards of biomedical innovation, human subjects have become an invaluable commodity necessary to fuel the engines of discovery. It therefore behooves us to consider carefully the circumstances in which we might be justified in invoking community interests against the rights of individuals.

The late Professor David Thomasma engaged with this issue in his essay published in a set of three volumes in this series on the topic of *Aging,* which I was privileged to co-edit with him (Weisstub et al. 2001a; 2001b; 2001c). He explored the question of "Community Consent for Research on the Impaired Elderly" (Thomasma 2001)[2] In that paper, he presented a strategy for entering subjects with a neurological impairment in research protocols through a process of community rather than personal consent. Professor Thomasma confirmed his commitment to the importance of respecting human rights, but also deferred to legitimate societal claims that derive from a communitarian ethic of social duty and responsible

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 341–352.

citizenship. He espoused the view that involving persons with impaired decision-making capacity as subjects need not diminish them as objects. Rather, he argued that, in allowing their participation in research that might benefit them or persons like them who suffered a similar disease, “there is no ‘dishonor’ in participating in research and, in fact, there may be honor attached to it” (id, 213). Of course, his advocacy for a model of community consent was balanced by strict ethical requirements through which he recognized that, although supporting the notion of an obligation to participate in research, there are reciprocal duties owed by researchers, carers and society generally towards vulnerable persons.

Thomasma’s reflection provides an excellent springboard for further inquiry on this important topic in health care and human rights, especially in light of the powerful forces driving biomedical innovation in contemporary health policy. To that end, I would raise an issue that I believe needs to be addressed before one can embark upon further debate about the ethics of community consent on behalf of persons lacking autonomous decision-making capacity, including children as well as cognitively impaired adults. One must examine the dominant justification for the involvement of such persons in research on the basis of surrogate consent: the so-called *research imperative*, which holds forth that research for the benefit of others can be of sufficient importance to warrant the infringement of the fundamental human right to personal inviolability. While this is not a new debate, asking “When, if ever, is it justified to use human subjects for research, considering that they also serve as means for the ends of others?” (Katz 1993: 34) remains a pivotal question in research ethics. Indeed, this theme has taken on renewed significance within the modern research enterprise by virtue of the transformation incurred by global forces, especially commercialization. This merits re-examining the foundations of the research imperative, confronting its influence in ethical decision-making and being alert to its potential for abuse.

FOUNDATIONS OF THE ‘RESEARCH IMPERATIVE’.

The view that research involving human subjects is ‘necessary’ is deeply entrenched. In the context of pediatric research, for example, it is recurringly emphasized that results obtained from studies of adult populations are not readily transferable owing to physiological and developmental differences (Institute of Medicine 2004: 58).[3] More generally, the importance of research involving human subjects is enunciated in a range of international ethical guidelines, including the *Declaration of Helsinki* since its inception in 1965. Article 4 of the current version (2000) states explicitly, “Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.”[4]

Such reasoning leads naturally to the proposition that “the prospect of discovering new ways of benefiting people’s health” provides an ethical justification for research (CIOMS 2002: guideline 1). This argument is not inherently problematic insofar as the goal of advancing knowledge to improve can be counterbalanced by other considerations promoting the rights of human subjects[5] That said, as I will argue in the next section, the process of balancing societal and individual interests in ethical decision-making is reliant on the characterization of and significance accorded to the 'importance' of research. The focus here relates to the problem that arises when societal interests are invoked to justify the involvement in research of persons lacking decision-making capacity, especially when the justification is rationalized in terms of a moral *obligation* to participate in such research.

At the heart of this issue lies the 'research imperative', which emerged from a classic exchange between Paul Ramsey (1976; 1977) and Richard McCormick (1976) in the *Hastings Center Report*. McCormick (1974) had argued that non-therapeutic research involving children could be morally justified, albeit within certain constraints. In brief, Ramsey disagreed, and presented a thought experiment that would construct the 'research imperative' as follows:

> Some sorts of human experimentation should…be acknowledged to be "borderline situations" in which moral agents are under the necessity of doing wrong for the sake of the public good. Either way they do wrong. It is immoral not to do the research. It is also immoral to use children who cannot themselves consent and who ought not to be presumed to consent to research unrelated to their treatment. On this supposition research in medicine, like politics, is a realm in which men have to "sin bravely." (Ramsey 1976: 21)

Thus, by appealing to a research *imperative,* public interests could override objections to dignitary violations (as well as to actual risks of harm) consequent to non-consensual interference with a person's bodily integrity. Of course, Ramsey did not support such a view. He upheld his earlier position that to enrol children in research on the basis of proxy consent was to treat a child as "an adult person who has consented to become a joint adventurer in the common cause of medical research." This, he believed, constituted "a violent and false presumption" (Ramsey 1970: 14).

In contrast, McCormick (1976) disagreed with the view that children were not moral agents. He argued that children, like adults, through their shared "sociality," have a duty to participate as subjects – if the level of risk, discomfort or pain is minimal or nonexistent[6] – and contribute to the advancement of knowledge towards the treatment of disease. Thus, while he would not endorse a research imperative as set out in Ramsey's thought experiment either, especially if it would promote research at any cost, McCormick (1976: 46) *would* support a formulation of the research imperative as follows:

> if it is right and charitable to heal the wounds of the wounded (as in the Good Samaritan);
>
> then it is at least as right and charitable to *prevent* them;
>
> and that if research is a necessary means in our time to *prevent* them (as, on all accounts it seems to be);
>
> then research (experimental procedures) is an imperative and indeed a Christian one.

In so doing, McCormick maintained his position that non-therapeutic research involving children was not only morally *permissible,* but was sustained by a nobler claim to a higher duty or obligation.

McCormick is not the only one to have argued this point. Instead of grounding his argument in the parable of the Good Samaritan, Arthur Caplan drew his concept of a duty to participate in research from a Rawlsian notion of "fair play" wherein he posited that, unless individuals take special efforts *not* to benefit from the sacrifices of others who have contributed to medical advances, they are obliged within a cooperativist ethic to reciprocate as volunteers in research. He noted that "few patients are innocent bystanders…Most actively seek out the highest quality care they can possibly receive, and in so doing, cement their status as obligated participants in an ongoing cooperative enterprise" (Caplan 1988: 239). This notion of reciprocity is likewise conveyed by the Institute of Medicine, which stated that participation in pediatric research is "essential if children are to share fully in the benefits derived from advances in medical science" (2004: 58). Thomasma also supported an obligation to participate in research, albeit on the basis of intergenerational responsibility:

> I will argue here that there is an obligation to participate in research that is stronger than the general obligation to "do something for humanity," but not so strong as to require that we all participate in research. The obligation flows from being a beneficiary of past generations of human beings who have participated in studies that have advanced the state of art of caring for the disease with which one finds oneself, and from the current dedication of caregivers who have devoted their lives to studying and caring for the class of patients in which one finds oneself. (Thomasma 2001: 213)

In contrast, Hans Jonas, like Ramsey, took the view that individuals have neither a social nor a moral obligation to participate in research. Jonas (1969: 231) argued that "The surrender of one's body to medical experimentation is entirely outside the enforceable 'social contract'." David Weisstub (1998: 26–27) likewise cautioned against invoking a social contract in the context of research involving vulnerable populations and warned of the potential excesses of a cooperativist ethic as portrayed by Caplan. In particular, he criticised the moral fiction of "making whole the fragile" by "indulging in the fiction that we can take all human beings, indeed on their behalf, into the realm of being made whole as moral beings" by calling upon them to perform charitable acts on behalf of others (id., 31–34).[7] Jonas held *self*-sacrifice as sacred and considered the imposition of a duty or obligation to act as a subject as amounting to "conscription." Even solicitation of participation based on a social duty, would detract, in his view, from its nobility and moral legitimacy. For Jonas, an individual can volunteer as a subject or be solicited to do so, but only if the research objective is both worthy and consistent with the subject's "own scheme of ends" (Jonas 1969). A person with a decision-making incapacity, such as a child or adult with a cognitive impairment, cannot make such a decision. To presume otherwise amounts to nothing more than a moral and legal fiction (see also: Gunn et al. 2000: 64; Lewis 2002: 590–2).

The force of the research imperative is such that it lends fuels to the rhetoric of a "war against disease," which supports a paradigm of research participation that would accommodate the conscription of human subjects, albeit under the veneer of a social duty or obligation. Callahan (2003: 62, 84) challenged the commonly asserted "war" metaphor in relation to ageing and death, arguing that avoiding death altogether "is not an appropriate medical target" and "that there is no social need to greatly extend life expectancy." He rightly referred to the arguments made by Jonas, who argued that there is no moral obligation to conduct research. As Jonas (1969: 245) admonished, "Let us not forget that progress is an optional goal, not an unconditional commitment, and…has nothing sacred about it." He argued that the goal of research is "essentially melioristic" and "in a sense gratuitous", both from the perspective of the subject, who cannot benefit directly from non-therapeutic research, and those that might benefit subsequently. As he aptly stated, "Our descendants have a right to be left an unplundered planet; they do not have a right to new miracle cures" (Jonas 1969: 230).

These objections by Jonas and Callahan go directly to the heart of the research imperative. They confront head-on the assertion that research involving human subjects is 'necessary' and the resultant claim that individuals have a societal duty to participate in research. While human experimentation may indeed be essential to the progress of medicine, it does not follow that the latter is also indispensable. And while it might be reasonable to assert that individuals ought to participate in research as matter of responsible citizenship or even social duty, it does not follow that altruism should be enforced as a positive duty or that individuals lacking decision-making capacity should be conscripted into the role of human subject.

A reasoned response to the 'research imperative,' therefore, is that, unless one is dealing with an epidemic, the demand for research is melioristic – desirable, but not vital. I argue that this presents a serious challenge to any proposition for community consent on behalf of persons lacking decision-making capacity that is derived from on a notion of obligation or duty. If worthy research of this nature is to proceed, then it will be necessary to locate its justification elsewhere.

THE 'IMPORTANCE' OF RESEARCH IN ETHICAL DECISION-MAKING

The Australian *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 1999: 10) is not unique in its directive to ethics committees in requiring that:

> In the assessment of the ethical acceptability of any research project, a committee should pay regard to the importance and the benefits of research and assess and balance these against the burdens undertaken by those participating in research.[8]

Such a directive identifies the 'importance' of research as an issue that committees must consider in assessing the ethical permissibility of involving human subjects in research.[9] It underscores the role of goal-based moral reasoning in ethics committee decision-making, which is distinct from rights-based and duty-based forms of moral reasoning that are more closely geared to either protecting subjects or enforcing obligations to protect them.[10] The 'importance of research' criterion, on the other hand, focuses on broader objectives than directly benefiting subjects.

Direct benefits to subjects would also be considered. However, even in studies where a subject might receive a therapeutic benefit – and it merits noting that until an experimental treatment achieves the status of therapy, a study can at best hold out a *potential* benefit[11] – the 'importance' of the research, measured in terms of the potential impact on persons *other* than the subject, remains part of the risk-benefit analysis.[12] In other scenarios, the importance of research can be the driving factor.

For example, where a study would compare an established therapy with an experimental treatment, the decision is, at least in theory, ethically neutral with respect to risks, since it is an ethical requirement that at the outset of the study the two alternatives are in equipoise.[13] What tips the scales in such cases in favour of proceeding with the study is the assertion that *potential* benefits (relative to risks) exceed those afforded by the existing treatment. Thus, 'importance' becomes the deciding factor. Likewise, for Phase I clinical trials or studies comparing a new treatment to a placebo (where no treatment exists), the subject cannot reasonably expect any benefit.[14] In such a situation, the 'importance' of the study is clearly the dominant consideration.

As goals are not generated in a vacuum, it follows that ethical decision-making by research ethics committees is fundamentally about balancing the interests of human subjects against those driving the research agenda.[15] A 'balancing' approach suggests, however, that the claims being advanced stand on an equal or comparable footing, with the societal objective attributed sufficient weight to be considered on the same plane as the fundamental human rights of subjects. Approving a protocol and accepting that research is 'important' implies that the risks faced by subjects are worth taking.

While this may not be entirely unreasonable, given that individual rights are not absolute in democratic societies, a question nevertheless arises about how 'importance' is valued in the ethical assessment of a study.[16] Any infringement of subjects' fundamental rights should be supported by equally strong justifications (Jonas 1969: 245).[17] Insofar as such a justification might derive from a societal endorsement of the importance of research, measured in terms of its capacity to serve the public good through the advancement of knowledge in biomedicine, this requirement might arguably be satisfied. However, as I concluded in the previous section, the goal of improving human health through research should not be accorded the status of an imperative, which through an indelicate utilitarian calculus would skew the risk-benefit analysis to grossly favour external aims over those of subjects.[18]

An uncritical acceptance of research as 'important' may have other more subtle ethically contentious implications. For example, a fervent (and presumably sincere) belief that research might provide important social benefits has served an exculpatory function in the history of human experimentation. It has helped to sustain such moral fictions as distinguishing between 'wrongness' and 'blameworthiness' in cases of research retrospectively deemed to be unethical, which was precisely the compromise reached by Advisory Commission on Human Radiation Experiments in their final report.[19] It is further illustrated by the treatment of scientific findings obtained from unethical studies. Both the Nazi data and their originators were cultivated in some way subsequent to the War. This includes the reintegration of Nazi scientists into military and industry hierarchies after the war and non-prosecution of Japanese doctors for their crimes against prisoners of war in China during World War II in exchange for disclosure of the results of their experiments.[20] The results of the Tuskegee Syphilis Study have likewise been incorporated into the scientific literature (Caplan 1992: 30).[21]

The weight attached to the 'importance of research' in ethical decision-making needs to be carefully managed, given its potential for misuse, as a tool for either directly imposing external interests or for the purpose of obfuscating their true nature.

Situations where the importance of research is promoted zealously to further aims unrelated to those of human subjects raise, at the very least, an issue of conflict of interests. As Callahan (2003: 132) observed, "The enthusiast for scientific research, believing it to be the royal road to human welfare, is likely to see benefits and risks differently from someone with a more modest view of science." The infamous Willowbrook Hepatitis and Jewish Chronic Disease Hospital Studies[22] provide extreme examples in which the investigators invoked a higher aim of benefiting humanity in their defense (Rothman 1991: 81). Such cases illustrate the potential for abuse not only of vulnerable subjects, but also of the societal justification itself.

The second concern relates to the transformation of societal interests in research outcomes. Governments have always been driven to develop knowledge and improve public health, which represents the classic societal aims in research. Both, however, have obvious economic ramifications. Healthcare advances can reduce hospitalization costs and technological innovation is a vital driver of modern economies, both in terms of creating jobs and building knowledge capital. A concern arises when states enter into the business of developing healthcare applications and knowledge, or when they defer responsibility for regulating such practices to the market.[23]

In the modern research enterprise, epistemological and melioristic goals, which were passionately defended by the "protagonists of research" at Nuremberg, are now wedded to a host of commercial and economic interests. As states increasingly emulate their industry partners, the lines between public and private interests in government-funded research have become increasingly blurred. This detracts from the sincerity of attempts to espouse societal claims in research. For example, in Canada, "facilitating commercialisation" and "promoting economic development" are two prominent statutory responsibilities of the Canadian Institutes of Health Research.[24] Putting pressure on public funding agencies to achieve commercially viable outcomes in effect benefits private interests – that is, the interests of industry. Societal and commercial aims are likewise blurred, no doubt strategically, by multinational pharmaceutical companies. This is evident from the current mission statement for Pfizer: "We dedicate ourselves to humanity's quest for longer, healthier, happier lives through innovation in pharmaceutical, consumer and animal health products."[25] As recognized in the landmark report by the House of Commons Health Committee in the United Kingdom (2005), however, research conducted by the pharmaceutical industry does not always serve the public interest.

One can readily imagine a situation where one might justify imposing controlled risks on individuals for societal benefits, such as in the case of mandatory vaccination programs or imposing a quarantine to contain a public health risk. The moral justification for conscripting individuals for commercial gains, however, is significantly harder to make out. While the machinery of biomedical research does produce significant economic output (Rosenberg 2002), stimulating economic development *in itself* is not a satisfactory justification for exposing subjects to risks, given that alternate means exist to stimulate economic growth or achieve commercial success that do not require the use of human subjects. In short, economic or commercial objectives cannot compete on the same moral plane as the classic societal justifications, limited as those justifications might be.

A more nuanced understanding of the 'research imperative' is thus helpful. Callahan (2003: 3) aptly defined the concept as "the felt drive to use research to gain various forms of knowledge for its own sake, or as a motive to achieve a worthy practical end." Within this broader definition, however, the research imperative can be employed to promote a range of objectives. Callahan (2003: 3–4) identified five:

"the drive to gain scientific knowledge for its own sake";

"a felt moral obligation to relieve pain and suffering";

"a rationale for pursuing research goals that are of doubtful human value or potentially harmful";

"a public relations tool to justify the chase after profit"; and

"the pursuit of worthy goals even at the risk of compromising important moral and social values."

The 'research imperative' is thus a powerful construct with broad implications for rationalising the research endeavour. It therefore becomes critical to acknowledge the potentially harmful effects of conflating private and public aims under the umbrella of societal claims within a so-called 'research imperative.' These can include the exploitation of legitimate altruistic inclinations of human subjects, and more significantly, causing ethics committees to over-estimate the 'importance' of research in the course of risk-benefit analysis. Finally, by placing inordinate emphasis on biomedical research as a social imperative, we run the risk of ignoring or diverting resources away from other social pursuits that could improve human well-being and quality of life (Callahan 2003: 2).

CONCLUSION

I accept that human experimentation is essential to advance scientific knowledge and thereby improve the longevity and quality of human lives. Yet, the pursuit of this laudable ambition can come into conflict with moral values to which we must be equally committed, such as the sanctity of life and individual autonomy. With mounting pressure internationally for improved health care in the face of constrained resources, the challenge *not* to use persons "as means for the ends of others" is becoming all the more difficult. This dilemma is especially poignant in the case of persons lacking decision-making capacity. As Professor Weisstub rightly observed,

> The choices we make about our vulnerable populations with respect to medical research test the fibre of the social values upon which we are prepared to base our society. If we are prepared to say that, in the public interest, we can make claims upon our vulnerable minorities, we must be prepared to relate our social policies to principles which reflect a consensus morality attached to certain core values, and to connect these principles to equitable procedures that facilitate a process which can be regarded as fair and just and not based simply on expediency or majoritarian interests. (Weisstub 1998: 2)

Protecting subjects requires a staunch commitment to fundamental human rights. It also requires sensitivity to the ways in which a combination of moral and legal fictions, deliberate or unintended obfuscations of professional roles or key concepts, and outright infringements of subjects' rights can damage whatever implicit trust remains in the integrity of science and medicine.[26] The importance of trust is invoked regularly as the basis for reforms in research ethics governance, whether to deregulate existing frameworks or enhance regulatory oversight.[27] Clarifying the manner in which the research endeavor and its underlying justifications are rationalized is instrumental to avoiding these problems and to preserving trust.

The key proposal I would advance in this response to Professor Thomasma's reflection is the 'importance' of promoting the primacy of the human rights of subjects over all external interests. I acknowledge that those rights are not absolute and, in limited circumstances, can be justifiably overridden. A resolution of this conflict, however, will only emerge from the continued evolution of research ethics governance frameworks that transparently define and delimit the force of societal aims in research, especially when these are invoked to override the fundamental rights of vulnerable human subjects.

NOTES

1. Human experimentation, as it has often been declared, is "as old as medicine itself" (i.e., Katz 1969: 481). Indeed, as Blumgart (1969: 44) observed, "every time a physician administers a drug to a patient, he is in a sense performing an experiment."
2. The cited paper by Professor Thomasma complements two others he had written on this area (Thomasma 1996; 2000).
3. Similar reasoning can be applied to other conditions, such as Alzheimer's Dememtia. On research involving cognitively impaired adults generally, see: Tomossy and Weisstub (1997: 116–9)
4. The latest revision of the *Declaration* clarifies further that the primary purpose of medical research involving human subjects is "to improve prophylactic, diagnostic and therapeutic procedures and the understanding of aetiology and pathogenesis of disease." Article 6 goes on to advance the necessity argument further: "Even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility and quality."
5. See: http://www.cioms.ch/frame_guidelines_nov_2002.htm (last accessed 13 Sept 2006).
6. Restricting research involving vulnerable populations to 'low', 'minimal' or 'negligible' risk is a standard ethical requirement in research ethics policies, although not without controversy. A further issue, however, remains in respect of the meaning of 'risk' in research (Weisstub et al 1998: 363–73).
7. Weisstub (1998: n54) argued that Caplan's Rawlsian assertion of an obligation to participate in research was deficient in the case of persons unable to provide consent owing to diminished decision-making capacity. Similar concerns have been acknowledged by Macklin and Sherwin (1975).
8. It should be noted that, at the time of writing, the 1999 Australian national guidelines were in the process of being revised. A revised set of guidelines is expected to emerge in late 2006 or early 2007. The second consultation draft of the revised guidelines retains the 'importance' of the aims of research (p. 10) under the heading of "risk" generally, as well as elsewhere in the document. See: http://www.nhmrc.gov.au/publications/_files/nsec2.pdf (last accessed: 13 Sept 2006).
9. Even at the conclusion of the Doctors Trial at Nuremberg following the Second World War, deference was given to the view that the practice of human experimentation, if kept within well-defined ethical boundaries, can "yield results for the good of society that are unprocurable by other methods or means of study." See: the preamble to the *Nuremberg Code,* which constituted part of the judgment resulting from *U.S.* v. *Karl Brandt et al., Trials of War Criminals Before the Nuremberg Military Tribunal Under Control Council Law No. 10,* Vol. 2, Nuremberg, October 1946 – April 1949. (Washington, DC: US Government Printing Office, 1949) pp. 181–2.
10. Ethics committees can be said to follow three main approaches to reasoning: goal-based, duty-based and rights-based. Foster (2001) proposed a hybrid approach to encompass all three, allowing for different levels of emphasis to be placed on each depending on a given case.

[11] See also the discussion on the importance of distinguishing research and therapy in Verdun-Jones and Weisstub (1998).

[12] Of course, subjects may also share in the broad aims of research, that is, the desire to produce societal benefits from their participation. However, a subject would not be permitted to enrol in a study involving extreme risks, even with their clear consent. It is expected that ethics committee approval would be based on an objective risk-benefit analysis of a study in general terms before even considering informed consent processes.

[13] Equipoise implies that both treatment alternatives hold out an equal likelihood of benefit (Freedman 1987). It is important to note, however, that the concept of 'equipoise' has been the subject of extensive scholarly critique (e.g.: Karlawish and Lantos 1997; Ashcroft 1999; Kahn 1999; Gifford 2001).

[14] This raises further concerns about the 'therapeutic misconception', which arises when a therapeutic benefit is incorrectly inferred from an experimental procedure (Appelbaum et al. 1982).

[15] As the Canadian guidelines state, "Modern research ethics…require a favourable harms-benefit balance – that is, that the foreseeable harms should not outweigh anticipated benefits" (Tri-Council 1998: i.6).

[16] That this decision is made independent of and prior to the informed consent process which involves subjects (or their proxies in present context of decisionally impaired subjects) is also important because subjects are only presented with a study once it has been sanctioned by an ethics committee, thus carrying with it an imprimatur of community approval. This is provided, of course, that ethics committees have been properly constituted to reflect community constituencies. This latter point would thus also be worth considering when reflecting upon a model of community consent for the cognitively impaired elderly.

[17] As Jonas (1969: 245) stated,

> We must justify the infringement of a primary inviolability, which needs no justification itself; and the justification of its infringement must be by values and needs of a dignity commensurate with those to be sacrificed.

[18] Indeed, as Callahan (2003: 113) aptly observed, to ignore the possibility that the war against disease will not lead down the path to eugenics "seems naïve."

[19] Though, this was noted by Beauchamp (1996) as constituting a shortcoming in the Commission's findings (see also: Tomossy 2006: 538–40).

[20] These topics have been treated extensively in the literature (Bower 1987; Brackman 1988; Williams and Wallace 1989).

[21] See also, however, Benedek and Erlen (1999) for a critique of the perils of historicism in relation to the Tuskegee Study.

[22] For a discussion of these studies, see Katz' seminal book on research ethics (Katz et al. 1972: 9–65).

[23] These patterns are evidenced when the success of a public health research initiative is measured not in terms of improvements to quality of life or life expectancy but by impact on health care expenditures, or when technical innovation is cultivated not just for the sake of knowledge in its own right, but as a commodity with market value under the rubric of the knowledge economy.

[24] See: *Canadian Institutes of Health Act*, S.C. 2000, c.6, s. 4(i). The CIHR replaced Canada's federal Medical Research Council.

[25] See: http://www.pfizer.com/pfizer/are/mn_about_mission.jsp (Last accessed: 13 Sept 2006).

[26] See, also, the excellent reflection by Illingworth (2005) on the moral costs of managed care.

[27] See, for example: (Kass et al. 1996; Institute of Medicine 2001; Yarborough and Sharp 2002; Gatter 2003).

REFERENCES

Appelbaum, P.S., Roth L.H. and Lidz C.W. 1982. The therapeutic misconception: informed consent in psychiatric research, *International Journal of Law and Psychiatry* 5(3–4): 319–329.

Ashcroft, R. 1999. Equipoise, knowledge and ethics in clinical research and practice, *Bioethics* 13(3–4): 314–326.

Beauchamp, T.L. 1996. Looking back and judging our predecessors, *Kennedy Institute of Ethics Journal* 6(3): 251–270.

Beecher, H.K. 1966. Ethics and clinical research, *New England Journal of Medicine* 274(24): 1354–1360.

Benedek, T.G. and Erlen J. 1999. The scientific environment of the Tuskegee Study of Syphilis, 1920–1960, *Perspectives in Biology and Medicine* 43(1): 1–30.

Blumgart, H.L. 1969. The medical framework for viewing the problem of human experimentation. In: *Experimentation With Human Subjects,* ed. Freund, P.A., pp 39–65. London: George Allen and Unwin.

Bower, T. 1987. *The Paperclip Conspiracy: The Battle for the Spoils and Secrets of Nazi Germany.* M. Joseph: London.

Brackman, A.C. 1988. *The Other Nuremberg: The Untold Story of the Tokyo War Crimes Trials.* Quill: New York.

Bynum, W. 1988. Reflections on the history of human experimentation. In: *The Use of Human Beings in Research: With Special Reference to Clinical Trials*, ed. Spicker, S.F., pp 29–46. Dordrecht: Kluwer Academic Publishers.

Callahan, D. 2003. What Price Better Health? *Hazards of the Research Imperative.* University of California Press: Berkeley.

Caplan, A.L. 1988. *Is there an obligation to participate in biomedical research? In: The Use of Human Beings in Research: With Special Reference to Clinical Trials*, ed. Spicker, S.F., pp 229–48. Dordrecht: Kluwer Academic Publishers.

——1992. Twenty years after. The legacy of the Tuskegee Syphilis Study. When evil intrudes, *Hastings Center Report* 22(6): 29–32.

CIOMS. 2002. *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva: CIOMS.

Commission for Macroeconomics and Health. 2001. *Macroeconomics and Health: Investing in Health for Economic Development*. Geneva: World Health Organization.

Foster, C. 2001. *The Ethics of Medical Research on Humans.* Cambridge University Press: Cambridge.

Freedman, B. 1987. Equipoise and the ethics of clinical research, *New England Journal of Medicine* 317(3): 141–145.

Funding First. 2002. *Exceptional Returns: The Economic Value of America's Investment in Medical Research.*

Gatter, R. 2003. Walking the talk of trust in human subjects research: The challenge of regulating financial conflicts of interest, *Emory Law Journal* 52: 327–401.

Gifford, F. 2001. Uncertainty about clinical equipoise. Clinical equipoise and the uncertainty principles both require further scrutiny, *British Medical Journal* 322(7289): 795.

Gunn, M.J. et al. 2000. Medical Research and Incompetent Adults, *Journal of Mental Health Law* 61–74.

House of Commons Health Committee (UK). 2005. *The Influence of the Pharmaceutical Industry*.

Illingworth, P.M.L. 2005. *Trusting Medicine: The Moral Cost of Managed Care*. Routledge: New York.

Institute of Medicine. 2001. *Preserving trust: Accreditation and human research participation protection programs*. Washington, D.C.: National Academy Press.

—— 2004. *Ethical Conduct of Clinical Research Involving Children*. National Academy Press: Washington, DC.

Jonas, H. 1969. Philosophical reflections on experimenting with human subjects, *Daedalus* 98(2): 219–247.

Kahn, J. 1999. Equipoise and the problem of research subjects with diminished capacity, *Accountability in Research* 7(2–4): 277–282.

Karlawish, J.H. and Lantos J. 1997. Community equipoise and the architecture of clinical research, *Cambridge Quarterly of Healthcare Ethics* 6(4): 385–396.

Kass, N.E. et al. 1996. Trust, The fragile foundation of contemporary biomedical research, *Hastings Center Report* 26(5): 25-29.

Katz, J. 1969. The education of the physician-investigator, *Daedalus* 98(2): 480–501.

Katz, J. 1993. Human experimentation and human rights, *St.Louis University Law Journal* 38(1): 7–54.

Katz, J., Capron A.M. and Glass E.S. 1972. *Experimentation with Human Beings: The Authority of the Investigator, Subject, Professions, and State in the Human Experimentation Process*. Russell Sage Foundation: New York.

Lederer, S.E. 1995. *Subjected to Science: Human Experimentation in America before the Second World War*. Johns Hopkins University Press: Baltimore.

Lewis, P. 2002. Procedures that are Against the Medical Interests of Incompetent Adults, *Oxford Journal of Legal Studies* 22(4): 575–618.

Macklin, R. and Sherwin S. 1975. Experimenting on human subjects: Philosophical perspectives, *Case Western Reserve Law Review* 25(3): 434–471.

Marks, H.M. 1997. *The Progress of Experiment: Science and Therapeutic Reform in the United States*, 1900–1990. Cambridge University Press: Cambridge England.

McCormick, R.A. 1974. Proxy consent in the experimentation situation, *Perspectives in Biology and Medicine* 18(1): 2–20.

––1976. Experimentation in children: sharing in sociality, *Hastings Center Report* 6(6): 41–46.

NHMRC. 1999. *National Statement on Ethical Conduct in Research Involving Humans.* National Health and Medical Research Council: Canberra.

Ramsey, P. 1970. *The Patient as Person.* Yale University Press: New Haven.

––1976. The enforcement of morals: nontherapeutic research on children, *Hastings Center Report* 6(4): 21–30.

––1977. Children as research subjects: a reply, *Hastings Center Report* 7(2): 40–42.

Rosenberg, L.E. 2002. Exceptional economic returns on investments in medical research, *Medical Journal of Australia* 177(7): 368–371.

Rothman, D.J. 1991. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. BasicBooks: New York.

Thomasma, D.C. 1996. A communal model for presumed consent for research on the neurologically vulnerable, *Accountability in Research* 4(3–4): 227–239.

––2000. A model of community substituted consent for research on the vulnerable, *Medicine, Health Care and Philosophy* 3(1): 47–57.

Thomasma, D.C. 2001. Community Consent for Research on the Impaired Elderly. In: *Aging: Decisions at the End of Life,* eds. Weisstub, D.N. Thomasma D.C., Gauthier S., and Tomossy G.F., pp 207–26. Dordrecht: Kluwer.

Tomossy, G.F. 2006. Vulnerability in research. In: *Disputes and Dilemmas in Health Law,* eds. Freckelton, I. and Petersen K., pp 534–59. Sydney: Federation Press.

Tomossy, G.F. and Weisstub D.N. 1997. The reform of adult guardianship laws: the case of non-therapeutic experimentation, *International Journal of Law and Psychiatry* 20(1): 113–139.

Tri-Council. 1998. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.* Ottawa, Ministry of Supply and Services.

Verdun-Jones, S.N. and Weisstub D.N. 1998. Drawing the Distinction Between Therapeutic Research and Non-Therapeutic Experimentation: Clearing a Way Through the Definitional Thicket. In: *Research on Human Subjects: Ethics, Law, and Social Policy,* ed. Weisstub, D.N., pp 111–36. Oxford, UK: Pergamon.

Weisstub, D.N. 1998. The ethical parameters of experimentation. In: *Research on Human Subjects: Ethics, Law, and Social Policy,* ed. Weisstub, D.N., pp 1–34. Oxford, UK: Pergamon.

Weisstub, D.N., Arboleda-Florez J., and Tomossy G.F. 1998. Establishing the boundaries of ethically permissible research with vulnerable populations. In: *Research on Human Subjects: Ethics, Law, and Social Policy,* ed. Weisstub, D.N., pp 355–79. Oxford, UK: Pergamon.

Weisstub, D.N., Thomasma D.C., Gauthier S., and Tomossy G.F. (eds), 2001a. *Aging: Caring for Our Elders.* Kluwer: Dordrecht.

–– 2001b. *Aging: Culture, Health and Social Change.* Kluwer: Dordrecht.

–– 2001c. *Aging: Decisions at the End of Life.* Kluwer: Dordrecht.

Williams, P., Wallace D., 1989. *Unit 731: Japan's Secret Biological Warfare in World War II.* Free Press: New York.

Yarborough, M. and Sharp R.R. 2002. Restoring and preserving trust in biomedical research, *Academic Medicine* 77(1): 8–14.

BRIAN MISHARA AND DAVID N.WEISSTUB

CHAPTER 24

THE RIGHTS TO DIE AND THE DUTY TO SAVE: A REFLECTION ON ETHICAL PRESUPPOSITIONS IN SUICIDE RESEARCH

This chapter examines the nature of ethical concerns regarding suicide research in the context of common ethical perspectives on the acceptability of suicidal behaviours and the obligations and limitations to intervening to prevent suicides. Suicide is a major health problem worldwide. According to World Health Organization data, almost one million people die by suicide each year (WHO 2002). There are more deaths by suicide annually than in all wars, conflicts, terrorist acts and homicides combined. Nevertheless, there are fewer research studies on suicide than many less common causes of mortality and several specific ethical considerations lead to limitations on the nature of research investigations which are conducted.

In suicide research, life and death is potentially at stake. For this reason research protocols may be held to a higher standard than studies of more innocuous issues. Ethical issues may influence whether or not specific studies are undertaken as well as the methodologies used and special precautions that are included. It is our premise that the resolution of ethical issues in suicide research is not simply based upon a direct application of existing guidelines. We contend that both explicit and implicit moral and ethical beliefs concerning suicide influence decisions concerning the design, methodology, interpretation and dissemination of research in suicidology, as well as decisions about what research is undertaken. We believe that clarification of the researcher's moral premises is essential in determining how common ethical issues in suicide research may be resolved.

This chapter is not meant to be exhaustive, but rather presents a number of typical situations with which researchers are confronted. The authors do not propose a specific moral position, but believe that there is utility in unpacking the implicit moral judgments and their ethical bases in understanding current practices and in determining future directions in suicidology research. Before examining the specific ethical dilemmas, several moral positions concerning suicide are described in order to permit analysis of the ethical issues within diverse contexts.

Ethical Perspectives to Guide Decision-Making Suicide prevention workers may be assumed to adhere to the principle that lives should be saved whenever possible, although the limits of their obligations to intervene and prevent may vary depending upon the worker and the circumstance. However, suicide researchers do not

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 353–373.

necessarily adhere to such beliefs. Furthermore, there is no coherent set of principles to which one can refer in order to attain consensual outcomes. Within existing research and clinical cultures we can expect to find the garden variety of philosophical orientations that are revealed in contemporary bioethical discussions (Weisstub 1998). The general ethical perspectives presented in this section are succinct stereotypes of alternative positions one may take concerning the moral acceptability or unacceptability of suicide as well as one's obligations and limitations to intervene to save a life. The philosophical basis of the morality of suicide has been the object of considerable debate for over two millennia. Several contemporary philosophical treatises discuss these issues in a sophisticated matter (e.g. Battin 1995). Our presentation of philosophical perspectives is intentionally stereotypical and ignores the subtleties of the rich debates among philosophers on these issues.

We present what could be termed popular paradigms in the ethics of suicide research culture in order to articulate how these points of view do or do not make a difference in applied situations. Although we feel that pure philosophical forms are unlikely to be commonly identified in situations where moral dilemmas are faced by researchers, we think it may be of real assistance for researchers to admit and communicate their own value derivatives and how they rationalize them in trying to resolve hard cases in suicide research ethics.

We have designated three broad categories in order to demarcate recurrent positions that are present in familiar discourse among suicide researchers. We designate them as moralist, libertarian and relativist. We present these stereotypical positions in order to reveal that there are a number of dominant perspectives that are the starting point for the way researchers position themselves in problematic or conflict situations. This article is only meant to address avenues of what could be called "“opening conversations,” ways of looking that should lead us to the demand for both greater dialogue and more extensive empirical research.

Moralist position Several philosophical traditions adhere to the moralist position that suicide is unacceptable and that there is a pervasive moral obligation to protect life. Arguments against the acceptability of suicide have a long tradition in several different philosophical currents. They may be based upon a religious philosophy in which it is sinful to take one's own life (Aquinas 1945) or obligation to protect life is based upon an individual's responsibilities to society (Plato 1955). Arguments against the acceptability of suicide need not be based upon religious or social obligations; for example they can include a justification on the basis of the "categorical imperative" of Kant (1949). Regardless of the basis of a moralist position, the general implication is that the protection of life constitutes an overriding value, which takes precedence in decision-making.

This value concerning the unacceptability of suicide has been commonly reflected in legal statutes rendering suicide and suicide attempts illegal acts. Although suicidal behaviors are still illegal in some countries (such as, in Singapore and Lebanon), many countries have decriminalized suicidal behaviors. For example, Canada decriminalized suicide in 1972 and England in 1961. However, most Western countries have laws against aiding and abetting suicides.

Although suicide is often decriminalized, many countries have some form of Good Samaritan law, which obliges citizens to intervene and save a life considered to be in danger. As long as they do not put their own life in risk, citizens are obliged under Good Samaritan laws to render assistance or to obtain help for people at risk of dying. These laws may be invoked to justify the necessity of stopping suicides by active interventions since they do not distinguish between self-inflicted deaths, accidental deaths and homicides.

Libertarian perspectives Libertarian perspectives emphasize the freedom of choice by individuals to determine whether or not to live or die. Libertarian perspectives vary in their philosophical basis from the hedonistic right to commit suicide to avoid pain and a wide range of utilitarian approaches, ranging from Hume (1929), to contemporary beliefs that the decision to live and die may be weighed rationally by a contemplative individual who is not currently suffering (Prado 1998). A more radical libertarian approach involves actually promoting suicide under certain circumstances, for example for those suffering from a painful or debilitating physical illness (Humphrey 1991). Regardless of whether the justification for a libertarian perspective concerns an obligation to avoid pain and displeasure or simple neutrality with respect to life and death decisions, the net result is that from a libertarian point of view there is no specific obligation to intervene and prevent a suicide.

The tendency towards a more libertarian perspective on suicide may be reflected in the decriminalization of suicidal behaviors in many countries. For some, legalization of the practice of euthanasia and assisted suicide constitutes an embodiment of this perspective and the legalization of these practices in some countries indicates its increasing influence. However, it is important to note that those who are proponents of euthanasia often distinguish between end of life decisions by the terminally ill and suicidal behavior by persons suffering from mental illness (Humphrey 1991). The overall implication of the libertarian perspective is that special precautions need not be made in the case of research on suicide.

Relativist approaches contextualists and consequentialists Relativist perspectives (Macklin 1999) determine the “rightness” or “wrongness” of suicide and the extent to which there are obligations to intervene to prevent suicide based upon either contemporary situational and cultural variables or the anticipated consequences of action or inaction. A large proportion of the general public may be considered common sense contextualists since they reply differently to questions about the acceptability of suicide depending upon the nature of the situation. For example, people generally find the suicide of an elderly person to be more acceptable than the suicide of a young person; suicide is generally more accepted when the person is suffering from a painful terminal illness than a healthy person.

Consequences, which may be used to justify intervention or non-intervention, may be at an individual, family or societal level. People justify suicides at the individual level by saying things like “he will be better off dead,” but suicide prevention centers use a different individual level justification for their interventions – even against a client’s wishes. They state that the common consequence of forced intervention is that callers call back later to thank them for saving their lives, which justifies their intrusive interventions. One may also justify interventions to save a life by taking into account benefits for the family.

In broad terms, the utilitarian ethic focuses on the best interests of society as understood in terms of the cost-benefit analysis based upon a calculation of utility rather than being restricted to the best interests of the person. Underlying the utilitarian ethic is the maximization of social utility as the vehicle to alleviate social misery. Social institutions are valued which can best accomplish this goal.

For the utilitarian, suicide may be sometimes viewed as an honorable behavior, which preserves and respects societal values, for example in the case of hara-kiri and kamikaze deaths in Japan. In other contexts, for example in the former Soviet Republics, suicide was viewed negatively because of the social deprivation of worker productivity. Therefore suicide was regarded as an aggression against state interests.

Regardless of the nature of the relativist perspectives, they all have the common characteristic that the obligation to protect life varies depending upon an analysis of the situation. These analyses may be in terms of an understanding of the context and culture, assessment of the consequences of practices for the victim, his or her milieu or society at large. Such reflection involves some form of cost-benefit (or risk-advantage) analysis of the situation, based upon principles ranging from individualist to communitarian values.

Ethics and Legal Considerations It must be noted that the positions presented here do not constitute nor entail legal necessities. What is morally justified is not equivalent to what is legally sanctioned, although in a utopian view of society one would expect a high level of convergence between law and ethics. When examining legal traditions, it is essential to distinguish between the common law tradition in English speaking countries and the European civil law approach.

English speaking jurisdictions (England, US., Canada, Australia, etc.) have been reluctant to date to declare a positive duty on citizens to rescue fellow citizens in the act of attempting suicide (Pardon 1998). When the act is less than imminent, common law judges have refused to allow the civil branch of law to state a firm rule, regardless of circumstances. At most, the common law has protected rescuers when it could be shown that persons attempting suicide have placed other citizens at risk through a type of negligent behavior. But the law has not compelled rescue behavior in itself (Franklin and Ploeger 2000).

Even where US states have enacted criminal law statutes prescribing Good Samaritan behavior, they have been meekly applied and only in dramatic circumstances (Pardon 1998). The overarching ethic of the common law, at least in the North American context, seems to have favored individual rights over any notion of collective duty (Ackerman 1995). The extent to which law should seek to reflect a popular or majority point of view, or should rather keep its historical categories of law relatively intact, is an ongoing controversy for legislators and judges alike. Suicide is an interesting example of this quandary. On the one hand, civil liability is less stigmatizing than a criminal law sanction for not intervening to prevent suicide. On the other hand civil recoveries in some areas, particularly the United States, have been of such magnitude that a significant part of the population could potentially be put in peril of bankruptcy if there were penalties for concerned citizens who have been either paralyzed or ineffectual in preventing or intervening with suicide attempts.

Although it is sometimes assumed in legal circles that Western Europe has had a longstanding history of Good Samaritan laws, influenced by a well-founded notion of the public good, it is in fact only in the nineteenth century that legislation in criminal codes appeared (in Russia, Tuscany, The Netherlands and Italy.) This was followed by further developments in the twentieth century. Following the Second World War almost every new criminal code in Europe contained failure to rescue provisions. Historical antecedents for Good Samaritan laws can be found in ancient Egyptian and Indian law, but it is notable that Roman law was unfavorably disposed to Good Samaritan legislation (Feldbrugge 1966).

Good Samaritan legislation ironically first made its appearance in France during the Second World War when it was in the interest of the German occupiers to provide incentives to reduce the effects of resistance against German forces (Ashworth and Steiner 1990). Although commentators have celebrated the European collectivist sensibility, closer scrutiny has revealed a restrictive interpretation of the statutes, to cases of present and actual danger, to motor accidents, failure of doctors and other healers to assist, recalcitrant parents of endangered children and individuals who have actively abetted suicidal acts (Ashworth and Steiner 1990). Moreover, one author has recently noted that there has been a shift away from strict interpretation of the Good Samaritan law in France (Pardun 1998).

Arguably, there is a strong cultural difference between the Protestant ethical foundations of culture in the US and the more communitarian European perspective. Thus, popular cultural expressions of individualism may be seen as in keeping with the non-interventionist US legal perspective. But, great anxiety has been expressed in the North American media that individualism has become so extreme that by-standers refuse to render aid. Nevertheless the English and European legal systems continue to remain faithful to their divergent pasts and it is likely that the individualist ethic will prevail in Anglo-Saxon jurisdictions for a considerable time.

Our analysis of legal obligations leads us to conclude that there is a global reluctance to hold individuals responsible for suicide rescue and failure of prevention and further reveal that legal statutes and decisions alone do not afford a simple or clear indication of public opinion or enforcement policies. In sum, legal statutes and decisions do not in and of themselves afford us a simple or clear direction either about public opinion or enforcement. It is interesting to speculate whether research cultures in North America and elsewhere are in any way influenced by their legal reference points. Correlating popular opinion and law or statutes as interpreted by judges is problematic at the best of times. Law and legislation can often conflict with one another or may precipitously change at any point in time. Making generalizations about legal cultures may prove to be meaningless insofar as there can be sustained tensions between criminal and civil law, such as in a host of American jurisdictions where there are criminal law statutes with respect to rescue, but no equivalent civil law duty (Groninger 1999). We contend that legal considerations rarely resolve ethical dilemmas; when meaningful resolution occurs, it is usually determined by internalized ethical standards. We now turn to an examination of some of those issues and dilemmas.

Vulnerability Suicide is related to vulnerability in the sense that many persons associated with the act fall into the classification of vulnerability as understood by such bodies as the Council for International Organizations of Medical Sciences, which in collaboration with the World Health Organization have issued "International Ethical Guidelines for Biomedical Research Involving Human Subjects" (CIOMS 2002). In the view of this body, vulnerability is connected to substantial incapacity to protect one's own interests, which can relate to a wide variety of problems. Usually, in the context of non-therapeutic experimentation, vulnerability is attached to the inability to protect oneself from exposure to an unreasonable risk of harm. In vulnerable populations there are questions of competence and voluntariness, which lead to concerns regarding the capacity to provide a valid and informed consent to participate in research. In the case of potentially suicidal individuals, we are never certain whether our interventions are intrinsically paternalistic and thereby morally unacceptable. Our social instinct is to regard the vast majority of suicidal individuals as vulnerable.

The moral arguments in suicide research lend themselves to even greater complexities than issues that arise among other so-called vulnerable populations. In suicide research the very issue at stake is often to study the extent of vulnerability, expressed as suicide risk. The issue is further complicated by the fact suicidal populations often overlap with other vulnerable groups, such as the mentally disordered and the elderly, which present specific challenges.

Research in suicide is often difficult to separate out from therapeutic interests. The idea that we can ever conduct pure research in suicidology may be an ideal, which is impossible to achieve. The justification of research thereby becomes a serious challenge when non-therapeutic research on potentially vulnerable populations is conducted. In the name of the principle of justice, the Belmont Report in 1978 required that subjects be selected for "reasons directly related to the problem being studied" rather than "simply because of their easy availability, their compromised position, or their manipulability" (National Commission 1978, 10). In the discussion of suicidology research that follows the implications of vulnerability is a recurrent theme, which is often the principal cause of concern, particularly the vulnerability that is expressed as an increased risk of suicide.

Experimental Methodologies For many, the "gold standard" for research is to conduct a random assignment study in which participants who are assigned to an experimental condition receive a treatment and those assigned to a control condition receive either no treatment or a placebo condition, which has no known specific effect related to the outcomes under investigation. In the case of suicide research, experimental methodologies involving no treatment control groups are rarely used because of ethical concerns. It is generally considered unethical to assign to a control non-treatment condition individuals who may be at risk of committing suicide in order to determine if an experimental treatment has a preventive effect. Because of this concern, it is common practice to exclude potentially suicidal individuals from participating in studies evaluating the effectiveness of new medications. This has resulted in the curious phenomenon that new drugs developed to treat mental health problems, which are commonly used in the treatment of suicidal individuals, have never been initially tested with persons at risk of suicide. Besides the ethical consideration of an obligation to treat persons at risk, there are also legal concerns, which may influence research designs in drug studies. If people die in the course of the evaluation of a new medication, the drug company may be held liable for their deaths.

An alternative to using a no-treatment control condition is to compare a new treatment with "treatment as usual" (TAU) (Degenholtz et al. 2002; Fisher et al. 2002). If there is no reason to assume on the basis of existing knowledge (theoretical equipoise) that the new treatment is better and there is a debate among clinicians as to which treatment is best (clinical equipoise) (Freedman 1987), one may assume that TAU methodologies do not expose the control group to added risks. However, in a situation where differences between treatments are not known, there is the potential risk in participating in any new treatment in the experimental group and there is a potential risk of being deprived of a beneficial intervention in the control group. After all, the researchers would not be undertaking the investigation if they did not have good reason to believe that the new treatment given to the experimental group offers significant benefits.

If one takes a strict moralist point of view, this exclusion from experimental methodologies with no treatment or placebo controls may be seen as essential because of an overriding obligation to protect people from suicide and preserve life. They would feel that one must always intervene in some way if there is a risk of suicide. However, they may feel differently about TAU studies, since all participants receive treatment. However, recent studies suggest that some standard treatments, such as the use of various SSRI medications for the treatment of depression, may not be effective in decreasing suicide risk and may even increase suicides in adolescents (Van Praag 2002). In this instance moralists would opt for ensuring that known effective treatments are always available, and if proof of effectiveness is not available, those treatments, which have been recommended by a consensus or majority of clinicians, can be offered.

From a libertarian perspective, individuals have the right to choose to live or die and also have the right to choose whether or not to put their lives at potential risk by participating in a research study involving a non-treatment control group. Since non-treatment controls may advance knowledge and help prevent lives in the future, they may choose to risk their lives in a noble manner to provide potential benefits for others in the future. Some moralists might have a similar view if they hold that people may sacrifice their lives in order to uphold a higher principle of benefiting humanity and saving many other lives.

Relativists would have to conduct analyses to ascertain whether or not experimental methodologies are justified in a specific instance. For example, one can weigh the potential risk in lives lost by participants in an experimental investigation against the potential benefits for many more individuals who could eventually benefit from the research results. This type of relativist analysis can only take place when there are sufficient data available to determine potential risks and benefits. In the case of established treatments in TAU designs, where some data are available, there may be a basis for undertaking an analysis of the possible risks and advantages. However, in the case of new interventions not previously evaluated, any analysis would have to be based upon theoretical beliefs or clinical judgments about what should or should not be helpful under certain circumstances. Furthermore, the practical issue of how to balance potential benefits against possible risks in terms of lives lost remains a controversial terrain where no guidelines currently exist.

It is possible that the risks, which would be of concern for relativists and moralists, may be decreased by the inclusion of increased surveillance of participants who participate in a research study and the inclusion of rescue procedures.

Rescue Procedures Most studies on suicide include some criteria for rescue of a potentially suicidal person under specified circumstances (Packman and Harris 1998). Even in a study that is not about intervention or prevention, a person may divulge information indicating that he or she, or a third party, is at risk of dying by suicide. Participants in studies unconcerned with intervention or prevention may divulge information indicating that they or a third party is a suicide risk, thus requiring that researchers refer to an intervention procedure should a participant's life be deemed endangered during a study.[1]

Researchers and clinicians are not currently able to accurately identify persons at risk of attempting and committing suicide (Hawton et al. 1998; Mishara and Tousignant 2004; Porkorny 1998). One of the important challenges in developing any rescue criteria is to determine to what extent false positives and false negatives are acceptable. If sensitive screening mechanisms or criteria are used to determine when to initiate rescue or intervention procedures, many more people will find themselves subjected to interventions or rescue services than are actually at high risk of killing themselves. It could be argued that implementation of more stringent rescue or intervention standards might distract energies to low risk individuals, while at the same time missing some who are truly suicidal.

Moralists would contend that it is imperative to include intervention and rescue criteria that are as sensitive as possible in order to save as many lives as possible. They would tend to minimize the dangers of subjecting some people who are not actually at risk to intrusive interventions, since moralists would feel that those dangers are minimal in comparison with the potential to save a life.

Libertarians would not ever instigate rescue or intervention procedures against the will of the participant. However, libertarians could respect existing guidelines by including a protocol where anyone determined to be at risk would be informed about potential sources of help and, if they so choose, the researchers may help them to obtain help. Even the most staunch libertarian would probably accept that information about potential sources of help should be given, with the participant in the research being free to contact or not contact the source of help if he/she so chooses.

The relativists could weigh the pros and cons, risks and benefits of various rescue procedures, given the risks of false positives and false negatives. Nevertheless, the relativist's analysis would be limited by the lack of specific knowledge of the risks and benefits and the reliability of suicide risk assessment procedures.

One of the practical challenges to rescue and intervention procedures relates to the clinical skills of the researchers. Some suicidology researchers are skilled clinicians with good diagnostic and intervention skills. However, other suicidology researchers do not have this background and would not be capable of intervening or conducting a good clinical assessment of the situation. In these instances there may be an obligation of researchers without clinical expertise to have clinicians or suicide prevention organizations involved in the study or at least available to intervene in suicidal crisis situations, which may occur in the course of the study.

Obtaining Informed Consent One of the most basic principles in conducting research is the obligation to obtain the informed consent of participants in which confidentiality is guaranteed. Confidentiality and privacy are also an explicit part of the process by mutual agreement between clients and helpers in many suicide prevention settings. However, in studies of high risk individuals confidentiality is usually not guaranteed or there are rescue procedures, which determine circumstances for breaking the confidentiality agreement to save a life. For example, calls to a suicidal crisis line involve an interaction with the helper in which confidence is developed and intimate details of the person's life are revealed. However, obtaining informed consent may compromise the help received in some instances. Imagine beginning a call from a person in a suicidal crisis by: "before we begin to discuss your problems, I would like to invite you to participate in a research study where people will be listening to the calls and assessing various characteristics of the helper and caller. This study is being conducted by professor x and has the objective of determining the effectiveness of the help provided…" Following such an introduction, lengthy information about confidentiality, whom to contact if there are issues about the research, etc., the objectives of the study, the possible risks and benefits, are divulged. Only after the aforementioned transaction the conversation continues with help being given to the suicidal caller.

It is evident that this detailed determination of the caller's consent to participate in the study could have a negative impact on suicidal callers' abilities to obtain immediate help for their problems in a secure and supportive situation. The helpers, who are fully aware that someone is listening to the call, may be overly tense or anxious about the researcher's assessment, thus hampering their ability to interact in the most helpful manner. Moreover, if such procedures were instituted, the result would be a likely sampling bias in which only those callers who are not in important crisis would accept to participate. On the other hand, because of the nature of the suicidal crisis and the desperate need of some callers to obtain help, some may feel greatly pressured to participate in the research for fear that they will be denied help. Inevitably, some seekers will feel that they will receive inadequate help or not be seen as sympathetic by the helper unless they agree to participate, even if they are reluctant collaborators.

How do the moralist, relativist and libertarian positions differentiate themselves in reacting to this situation? A strongly moralist position would suggest that anything that could potentially risk compromising the ability of suicidal people to obtain help should not be undertaken. However, a moralist might also be very much concerned by the necessity to obtain non-biased evaluations of the quality of help received by suicidal people. Because of the overriding necessity for moralists to save lives under all circumstances, a moralist would probably be more likely to favor compromising ethical obligations for informed consent in order to ensure better quality services and non-interference with crisis interventions. They may be more likely to accept a practice of listening to calls without informing callers or helpers. A compromise position might be to have a tape-recorded announcement informing callers that the call may be monitored, so at least callers would be made aware of potential of actual third party monitoring.

A libertarian could approach this situation from various perspectives. The libertarian might feel it is essential that a suicidal person have the free choice to participate or not participate in any research study and that full explanation and informed consent is essential. However, a libertarian could equally hold that persons experiencing a suicidal crisis should have the liberty to seek help to resolve their crises without interference from intrusive research practices. Libertarians might therefore not accept any practices compromising the quality of the help that callers should be able to receive. They could also, like the moralists, be concerned that if research were not conducted it would block the development of quality services when persons freely choose to contact a help line.

Relativists would inevitably weigh the potential benefits against the potential harm caused by various practices. They may compare the possible dangers of conducting a research investigation in which data are obtained on someone without their consent, against the potential benefits of doing so, the relative harm of providing information to obtain informed consent versus the potential benefits of the study, etc. Alas, it is often the case that there are insufficient data to undertake such analyses. For example, in a silent monitoring study conducted by one of the authors of this paper, the decision was made to inform callers of the possibility of monitoring calls in a tape recorded announcement preceding connection to the helper at the crisis line. In initial discussions of this practice with crisis centers, many were concerned that callers who hear this announcement would hang up and they would not receive critical assistance. It should be noted, however, that crisis centers that already used such tape-recorded messages reported no increase in hang-ups, except possibly a decrease in the number of "sex" calls. Empirical assessments during the course of the study did not indicate any increase in hang-ups when this message was included. In this instance, admittedly, there were data from previous studies. However, there are many areas for which no previous experience exists. In these cases, one may argue about potential consequences but the basis for decisions remains arbitrary.

Deception and Disclosure Studies involving deceptive practices generally need to be justified as causing minimal or no harm, as well as being necessary because no other means of obtaining the information without deception are available and the information sought is judged to be of scientific or practical importance. In the case of the silent monitoring of calls to crisis centers, one of the methodological procedures proposed to avoid the problems involved in informed consent procedures was to have a trained actor place fictional calls to crisis centers in which she pretends to be a suicidal person in crisis, and where researchers would monitor those calls. If the goal is to evaluate the quality of telephone interventions (if helpers do what they are supposed to be doing to help suicidal callers according to generally accepted models of intervention and have beneficial characteristics, such as empathy), this method of having "false" calls may obtain this information in a relatively simple manner. This procedure could only be useful if the actor were convincing and if the helpers who receive the calls do not know that these are not "real" calls. Although no suicidal person is directly in danger when fictitious calls are used, some risks may be identified: First, this practice involves deception of helpers. In this instance it should be pointed out that during a fictional call real suicidal persons might not have access to the helper who is occupied with the fictional caller. This could put suicidal individuals at greater risk if it compromises their ability to receive immediate help in a crisis situation. Furthermore, helpers should have the right to freely consent to participate in a research project. Finally, these calls are not without potential negative consequences. Helpers may experience the added stress of having to handle the call from a person they think is really at risk of killing himself.

Moralists may justify such deception and lack of informed consent by their primary concern for saving lives. However, if there is a possibility that lives may be lost because the phone is occupied with a fictitious call, they may not be in favor of this practice. In their analysis the moralists might find themselves weighing the potential risks against the potential benefits in order to make a decision and thus find themselves sliding towards a more relativist stance. The libertarian would seem to want the helper to make a clear informed choice as to whether to participate in the study or not. However, a libertarian concerned with having help available for those who choose to seek help could find this study useful in guaranteeing the right to quality services. They also may find themselves looking at relative risks and benefits for the caller. The relativists again may find it hard to have sufficient data to evaluate the advantages and disadvantages or consequences of this practice. It would be difficult to determine if the helpers were significantly stressed by the calls without actually conducting the study and measuring their stress. In fact, we know very little about the long-term effects of stress upon telephone helpers. We also do not know with any surety how important it is for a caller in a crisis to reach a helper immediately. Some may feel that if help were not immediately available, the person is at risk of committing suicide. Others may view the suicidal crisis differently and feel that those who would truly benefit from help are those who are known to persistently call until help is obtained.

Innovative and Unproven Interventions One of the greatest challenges in suicidology research is to test innovative and unproven interventions whose effects are yet unknown. Because of possible paradoxical effects of increasing suicide risk, there may be hesitation to try anything new and conduct research on innovative practices. Although logical and theoretical justifications for practices may seem strong, there are known paradoxical effects in suicidology. For example, one may think that showing photographs of persons who died by suicide in newspapers and magazines could dissuade potential victims because of the graphic depiction of death. However, research has determined that when photographs showing how people kill themselves are published, there is an increased likelihood of copycat suicides (Stack 2000). In the past, there was much reticence in asking direct questions to depressed and vulnerable clients about whether or not they were thinking of killing themselves because of the belief that this may "put ideas in people's minds." It is now generally accepted that asking direct questions does not increase suicide risk. Asking direct questions is considered to be essential in assessing the suicide risk.

If we do not have any firm data on the effects of a practice, and if our main concern is protecting human life, there may be a general tendency to avoid trying something new because of the potential risks. The same moralist who holds that life should be protected at all cost may be conflicted about the potential risks of an untried practice versus the imperative to find better ways to save people's lives. Libertarians may feel that people should choose for themselves, whether or not new practices are acceptable. However, they may justifiably realize that people would not have sufficient information upon which to choose. Even the relativists may find that there is little concrete information to make any form of contextual or consequentialist analysis.

Choice of Participants .Unknown Effects of Participation We have already discussed the elimination of participants who are at risk of suicide from studies involving experimental methodologies. However, the potential effects on participants are not limited to situations where there are treatment and non-treatment groups. Any gathering of research information may have an effect upon the suicidal risk of a participant. Bringing up memories of the circumstances surrounding suicidal intentions or attempts may either have benefits for a participant or may result in increased risk. Again, the empirical data are lacking in most situations and researchers must rely upon clinical insights or careful monitoring as a study progresses. The libertarian would feel that if informed consent is obtained people might simply choose to participate or not. Moralists on the other hand, may put more emphasis on the researcher's obligation to ensure that potential participants are not placed at greater risk. Relativists may emphasize measuring risks and weighing them against possible benefits.

Disclosure of Information Concerning Suicide Risk of Third Parties In the course of research on suicide, researchers may learn that specific individuals, families or milieus carry with them a high risk of suicide. We have already discussed rescue and intervention procedures when a participant in a study is likely to attempt or commit suicide. However, often the information obtained does not directly concern the participant but concerns others. This is common in survey and interview studies where participants are asked about their contacts with suicidal persons. A case in point: During a suicide investigation of an adult, a participant confides that a family member appears to be at high suicide risk. Does confidentiality require researchers to inform the participant about available help, urge him or her to contact help sources and encourage the suicidal individual to contact the researchers? Since confidentiality has been promised, some researchers will limit their actions to informing the participant about sources of help and inviting the participant to contact those sources and encourage the person at risk to contact them as well. But, can the obligations of researchers extend even further? If it appears that the other person is likely to kill him or herself in the near future, and if the participant is not willing to become involved or seek help, does the researcher have any further obligation or are researchers limited by their confidentiality agreement?

Moralists at first blush might wish, in favor of intervention, to push researchers, maintaining that the principle of confidentiality has a lower priority than the overriding obligation of protecting human life. On reflection, the information, although it may seem reliable, will be exposed in many contexts as hearsay, and refers to the subjective interpretation of the informer. The researcher does not have direct information concerning the person who is possibly at risk. Would the moralist feel so strongly that one should send rescue services for persons never encountered? The libertarian would want to respect the rights of the suspected suicidal individual and all interventions without the person directly requesting help might appear to impinge upon the person's liberty to choose. However, what if the situation is more complex: namely that the third party appears distressed and is asking for help? Would it significantly alter the context if the person suffers from a serious mental health problem, for example, schizophrenia, with the person hearing voices telling him to kill himself? Are there circumstances where the commitment to liberty is compromised by a serious mental health problem? It is in fact rare to find libertarians who hold to an absolutist position in view of overwhelming evidence of clear and present mental distortion. For the relativist, one may wonder which variables could show that intervention is indicated or not. In an ethnic community where privacy is strictly respected, would intervention be less appropriate than in another ethnic community where there is a high level of community interaction? Would it matter why the person was intending to commit suicide? If the person were dying from cancer and 80 years old would this be more likely to indicate non-intervention, compared to a young professional man in good health in crisis after being abandoned by his girlfriend?

Most researchers accept that there are special requirements for disclosure in the case of minors. These requirements are often ensconced in laws, which mandate reporting of situations where a child is at risk of not just suicide, but in any situation where there is a danger to the child's physical or mental health. In most western liberal democracies, there are legal obligations that override one's moral position. Would a libertarian feel that a minor, someone under age 18 or 16 depending upon the locality should also be free to choose to live or die without intervention? For the moralist it appears clear. However, are there instances where the effects of identifying someone as suicidal and letting this be known produces more risk than non-intervention? Would the relativist be likely to put aside his/her evaluation of whatever factors they feel may be important when minors are involved and take a more moralist position? Or would the relativist continue to assess the importance of intervening depending upon the specific circumstances?

Special populations The issue of inclusion of at-risk participants and obtaining informed consent becomes even more complicated with special populations, including children and emancipated minors, patients in psychiatric hospitals, prisoners and persons bereaved by suicide. External pressures in institutional settings, such as special privileges for prisoners or psychiatric patients who participate in research, pressure from staff who are in a powerful position, and feelings of guilt by those bereaved by suicide, may significantly influence the decision to participate in a research study. In these instances one may question whether informed consent is ever unencumbered by undue external influence. Can one justify testing potentially dangerous new interventions on prisoners in order to benefit the rest of society? Are prisoners, from a libertarian perspective, truly free to choose to participate in a research study or not? Should their lives be protected as moralists might contend, at all costs, like anyone else's? Or is the moralist position clear in its direction, given that a moralist might devalue rights based upon the notion of social paybacks built into the equation of punishment? How does one calculate the relative benefits and for whom?

Very often issues concerning special populations are overly determined by existing legal constraints. However, the legal issue of whether a person is competent to participate or not may diverge from ethical or functional criteria for competent decision-making. For example in the case of emancipated minors, they may have the legal right to participate as adults, but there are indications that their rights need special protection by inclusion of child specialists in determining research protocols (Rubenstein 2004).

Whatever the ethical perspective, be it moralist, libertarian or relativist, the issues remain daunting. For the moralist, it may not be an easy task to determine which behaviors should result in life protection when it comes to identifying people as potentially suicidal. Relativists may find it hard to determine what to weigh in situations where few data are available. Libertarians may emphasize the importance of a person having the right to information and make informed choices. However, if the information is unreliable, this information may compromise one's ability to choose freely. Also, it is important to determine what constitutes sufficient accuracy and reliability of any form of tests and measures for determining who is suicidal. The analysis from a relativist position can be undertaken again at different levels. One could weigh the values of informing people of their diagnosis or potential for suicide for the individuals, their families or society at large.

The Interpretation and Diffusion of Results It is well documented that publicity about death by suicide may have the potential of increasing suicides among vulnerable populations who are exposed to that publicity (Stack 2000; 2002). What are the actual positive and negative effects of diffusing research results? Consider research findings that people possessing certain characteristics are at greater risk of suicide. This may increase anxiety and concern among these groups and fuel their social stigmatization. The same may be true when studies show higher suicide risks in some environments. For example, media reports of a cluster of suicides in a Quebec town resulted in a flurry of spectacular reporting on a possible suicide "epidemic." The town was in crisis, parents withdrew their children from the local High School and it took well over a year before researchers determined that this cluster of suicides involved unrelated incidents and that there appeared to be no risk factors related to the school environment. However even if there were a greater risk in a school, publicizing research about this may have the negative effect of increasing anxiety in students and parents, without resolving the inherent difficulties (Mishara 2003).

Moralists would find themselves forced to evaluate the research findings in order to determine if there are risks of increased suicide associated with diffusing certain results or if there are benefits in terms of potentially saving lives. They might find themselves involved in relativist analyses to determine what to do. Libertarians might tend to ignore potential risks and invoke arguments about "the right to know" and thus might diffuse all results regardless of the consequences.

Special Issues in Evaluative Research There are numerous general issues in evaluative research, some of which are not specific to suicidology (Mishara 2004). Very often the goals of the evaluation are different from the perspective of those involved. The focus of the evaluation may need to be adjusted depending upon different needs. For the evaluators, who are outside researchers, their goal may be to conduct as scientific an evaluation as possible in order to obtain reliable and valid information that can be accepted for publication in academic journals. For the Board of Directors, the goal may be to improve practices. They may have other specific goals, as in justifying the termination of some staff members or obtaining information to assist in funding requests. The Director and administration of the agency may be concerned with cost cutting or improving efficiency, or simply wishing to impress the Board of the Directors that they are doing an exemplary job. Employees might view an evaluation as an opportunity to express their complaints to obtain better working conditions. Equally, they could be threatened by the evaluation since their activities could come under scrutiny.

There are specific ethical issues that arise from conflicts among evaluation objectives. For example, a skilled researcher can develop a client satisfaction questionnaire that is almost certain to obtain positive results that administrators can use to justify funding requests. In the area of suicide prevention, one is hard pressed to locate a client satisfaction survey having not produced extremely positive results. Therefore, the validity and usefulness of client surveys may be frequently questioned.

In evaluation research, analyses are often undertaken in which the cost of the activity is weighed against its potential benefits. Funding agencies need to decide whether it is "worthwhile" to fund specific programs. Evaluators provide important information that assists in making decisions about funding and program development. However, in the area of suicide prevention, how is it possible to measure what it is worth to potentially save human lives? For a strong moralist, the value of saving even one life justifies enormous effort and expense. But moralists are not supported by unlimited funding and resources. If agencies must choose between funding a very costly program to save a few lives versus funding a less expensive program having the potential of saving many more lives, should the moralist opt for the program saving the most lives? The libertarian, no matter how much she or he believes in the choice to kill oneself, would be expected to encourage making programs available allowing persons to choose to seek help for their problems. Therefore, in analyses of the costs and benefits of suicide prevention programs, libertarians would be likely to favor programs that are reactive to the needs of clients rather than more proactive programs seeking out to help people who may be resistant.

Evaluators are faced with the challenge of deciding how to present analyses of the costs and benefits of suicide prevention. If their philosophical perspective were more libertarian, there would be a tendency to prioritize variables related to clients' freedom. Moralist oriented evaluators would look carefully at the potential of programs to save lives. However, when comparisons are made between programs, the issue becomes more complex when the lives saved do not come from the same population. If funding is limited, would it be best to finance a program having a high potential of saving the lives of elderly suicidal cancer patients as opposed to an equally expensive program having the potential of saving fewer lives, but of people in the prime of life and in good health? Is it not a safe assumption that most people would respond that it is the latter program that should be financed? If this is the case, as a society, regardless of our expressed value system, we conflate ourselves with the relativist perspective in which some lives are viewed as more valued and worthy of saving than others. A strict moralist would eschew this contention and claim that all lives are equally valued and must be saved "at all costs." However, we are forced to deal with the reality that as a society we are provided with limited resources. Must moralists then be forced to compromise their values and prioritize which lives are more valued to save?

The evaluator is faced with these issues in determining not only what type of information to collect in the process of an evaluation, but the type of cost-benefit analyses they may undertake and the manner in which they interpret those findings. For example, the Centre for Disease Control of the United States, in a conference comparing suicide prevention strategies, said that they were looking for programs offering "more bang for the dollar (National Conference on Youth Suicide 1985)". Such a statement appears to reflect the view that the more lives saved, the better the program. However, is there not a moral obligation to invest in less efficient programs to meet the suicide prevention needs of specific sub-populations? For example, even if it were determined much less cost efficient, might it be important to offer more programs to native aboriginal peoples or other minority groups?

Although evaluators pretend to be neutral about such issues, their values and beliefs concerning the rights and obligations of various sub-groups of the population are implicit in any evaluation activity.

For the ethical reason of protecting the participation of individuals and organizations in evaluating activities, and in order to obtain accurate information without bias, confidentiality is usually guaranteed for all parties. What should be done though when information is obtained in the course of the evaluation indicating that lives may be inadvertently lost because of poor practices? For example, should confidential information be disclosed if, in the course of a silent monitoring study, where researchers listen to telephone interventions, the researchers learn of helpers encouraging people to kill themselves? What if it is determined that some helpers are not conducting adequate interventions and can be identified by the researchers? What if the researchers learn that a telephone helper interrupts to take personal calls on a cell phone? Such practices may be deemed dangerous if continued. In other instances it may not be clear to what extent life is actually endangered. Sometimes, such information is actually part of the evaluative study, for example if some telephone helpers are observed to be less effective than others in a study of the effectiveness of telephone help. In other situations the information obtained is peripheral to the data collected as part of the evaluation, as in one worker telling the evaluator that a co-worker is behaving negligently.

For the moralist, must all the information obtained be divulged in order to save the lives of callers, regardless of promises on the part of the researchers to have all information strictly confidential? This may have implications for the evaluative research design, specifically where the evaluators design their research tools disguising or deleting any identifying information. For the libertarian, one would think that there would be a leaning towards respecting confidentiality guarantees since the choice to live or die is an individual decision made by a suicidal person. However, if individuals have the liberty to choose to seek help for their problems, might there not be an implied obligation to ensure that the help received is competent? The Relativist's analysis of disclosure vs. non-disclosure would inevitably be elaborate. It may be determined that disclosing that a specific person is not doing a good job would result in that person being replaced by a more competent individual who may save more lives. In addition to the violation of an ethical undertaking, the entire evaluation study may be compromised by the fact that it becomes known that the evaluators are not respecting confidentiality. This may result in not obtaining important information that could help determine how to better save lives in the future.

One of the important issues in evaluative research is to determine who may use the evaluation results and under what circumstances. In some situations, the evaluation results "belong" to the researchers who may publish them and diffuse the information in any way they please. In other situations, the report is submitted to a Board of Directors, a Funding Agency, or Administrators who may then choose to diffuse all or part of the results as they see fit. It is not unusual that there are conflicts over who has the right to use the evaluation and in which manner. One of the issues facing an evaluator is the extent to which he or she has an obligation to disseminate the results regardless of what they indicate.

Does the evaluator have a moral obligation to consider the effects of dissemination of all or parts of the results, and to consider the manner in which the results are interpreted? Very often the manner in which results are presented depends upon how the evaluators view the findings. A practical and ethical dilemma occurs when, for example, the evaluation of a community's only suicide prevention program indicates that there are serious deficiencies? If this is disseminated, clients may stop seeking help at that agency because they feel they will not get good services. They may not sufficiently comprehend that despite the deficiencies, there is still a net value in continued consultation. Community politicians motivated to cut spending may be likely to set suicide prevention aside rather than improve services in the event that a negative evaluation report is proffered. This points to the fact that evaluation data are not simple facts. The way in which they are presented and interpreted may have an important influence on practices and eventually the saving of lives.

Would a moralist condone downplaying negative results so that an organization can continue functioning and helping prevent suicides? Accurate dissemination of results, which could induce policy makes to limit services, might nonetheless ultimately save more lives by bringing about better suicide prevention practices. Would the libertarian perspective suggest that research results should be disseminated in as neutral a manner as possible, without any further deliberations or calculations? Researchers must interpret findings whenever the covert influence of personal philosophies exists. The Relativist might examine the specific situation, but it may not be at all clear which variables take precedence for effective policy making, regardless of any pre-existing hierarchy of current social values.

CONCLUSIONS AND RECOMMENDATIONS

The examples in this article illustrate the extent to which ethical perspectives on suicide may influence decisions by researchers in their choice of whether or not to conduct a research investigation as well as the design, conduct and diffusion of their studies. Although our stereotypical ethical perspectives of the moralist, libertarian and relativist are useful in understanding how decisions can and have been made, it is evident that having a clearly defined moral stance is not, in and of itself, sufficient to determine what to do when faced with important ethical dilemmas in the course of suicidology research. Morality, as expressed in the philosophical realm, is removed from the constraints and practicalities of funding decisions, obtaining the confidence of participants so that research can proceed, and trying to determine if someone is actually at risk of suicide. Because of these considerations, those holding any one of these philosophical perspectives are forced to integrate some aspects of opposing or conflictual points of view.

The strict moralist who believes that lives must be saved at any cost is induced to evaluate whose lives are more valued if there are insufficient resources. The moralist might claim to be neutral under those circumstances, saying that all lives are of equal value. However, in reality, few moralists would invest as much to save the life of a condemned multiple murderer as opposed to a productive citizen. Libertarians may claim to be neutral concerning the right to live and die; leaving it to each individual's personal discretion. However, part of the concept of liberty to choose involves the liberty to seek help. Is there not an implied understanding on the part of the libertarians to help individuals express choice through seeking help based on quality services? Libertarians are also confronted with the challenges of special populations who may be considered incompetent to exercise their free choice or may be under pressure to choose to live or die. For example, if a person chooses to die because of intolerable pain and suffering in a society where pain control is not an acceptable practice, is this a free choice? In a cult where the leader has brainwashed members into following his every whim, if the leader orders people to kill themselves, do the members freely choose to die? Is freedom to choose to die extended to minors or are there parental obligations to save their lives? Relativists may accommodate certain other situations where intervention is obligatory or where people should be left to decide. However, in situations where we do not have sufficient knowledge to determine if the circumstances meet their criteria, might it be best to try to save everyone and slide towards a moralist position, or rather let each person be free to choose as a libertarian would espouse?

One of the ways by which researchers may avoid some of the pitfalls of ethical issues is to clarify in advance their moral stance concerning suicide and its implications for their research practices. Either in a description of the research project, the research proposal, or a contract to conduct an evaluation between the evaluator and the organizations involved, it is possible to set out the ethical values that are to govern the research being undertaken. We suggest that the statement of values may begin with a position concerning the morality of suicide and the ethics of prevention and intervention. The researchers may then elaborate on relative aspects of their activities involving ethical issues, stating how they will be resolved. Furthermore, they may state in specific terms how some of these issues will be handled. Such a document could include a statement of whether or not confidential information will ever be disclosed, and if so to whom, in what manner, and under what circumstances. Rescue procedures for participants may be described, including the criteria to be employed for rescue as well as the nature of the rescue activities that are to be made available. This may also include a description of to whom the results would be communicated, who may use the results and in what manner. Finally, they may state what will occur if negative findings are obtained or if situations arise, which may increase the probability of suicide either indirectly or directly.

This article has explored how ethical presuppositions concerning suicide influence research practices. It is our hope this will stimulate further discussion of the relationships between ethical and legal positions, and their implications for research. Considerations of these issues may avoid potentially difficult situations that could negatively affect investigations. The handling of these ethical issues will inevitably impact on the lives and deaths of suicidal persons who are both involved in the research, as well as those who could benefit from the results.

NOTES

[1] See http://www.nimh.nih.gov/research/safetymonitoring.cfm.

REFERENCES

Ackerman, R.M. (1995). Tort law and communitarianism: Where rights meet responsibilities. *Wake Forest Law Review,* 30, 649–661.

Aquinas, Th. (1945). *The Basic Writings of St-Thomas Aquinas, 2 vols*. Transl. and notes A.C. Pegis. New York: Random House.

Ashworth, A., & Steiner, E. (1990). Criminal omissions and public duties: The Freud experience. *Legal Studies,* 10, 153–164.

Battin, M.P. (1995). *Ethical Issues in Suicide*. Englewood Cliffs, New Jersey: Prentice-Hall.

CIOMS. (2002). *Intentional Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva: Council for International Organizations of Medical Sciences.

Degenholtz, H.B., Parker, L.S., & Reynolds, C.F. (2002). Trial design and informed consent for a clinic-based study with a treatment as usual control arm. *Ethics and Behavior,* 12(1), 43–62.

Feldbrugge, F.J.M. (1966). Good and bad Samaritans: A comparative survey of criminal law provisions concerning failure to rescue. *American Journal of Comparative Law*, 14, 630.

Fisher, C.B., Pearson, J.L., Kim, S., & Reynolds, C.F. (2002). Ethical issues in including suicidal individuals in clinical research. *IRB : Ethics & Human Research,* 24(5), 9–14.

Franklin, M.A., & Ploeger, M. (2000). Of rescue and report: Should tort Law impose a duty to help endangered persons or abused children. *Santa Clara Law Review,* 40, 991–1026.

Freedman, B. (1987). Equipoise and the ethics of clinical research. *New England Journal of Medicine*, 187, 141–145.

Groninger, J.L. (1999). No duty to rescue: Can America really leave a victim lying in the street? What is left of the American rule, and will it survive unabated? *Pepperdine Law Review*, 353–378.

Hawton, K., Arensman, E., et al. (1998). Deliberate self-harm: Systematic review of efficacy of psychosocial and pharmacological treatments in preventing repetition. *British Medical Journal*, 317, 441–447.

Hume, D. (1929). *An Essay on Suicide (1789)*. Yellow Spring (OH): Kahoe and Co.

Humphrey, D. (1991). *Final Exit*. Eugene, Oregon: The Hemlock Society.

Kant, I. (1949). *Fundamental Principles of the Metaphysics of Morals*, transl. J.K. Abbott New York: Liberal Art Press.

MacKlin, R. (1999). *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine.* Oxford: Oxford University Press.

Mishara, B.L. (2003). Des pratiques novatrices pour la prévention du suicide au Québec: un défi de société. *Santé Mentale au Québec*, XXVIII(1), 111–125.

Mishara, B.L. (2004). Les questions éthiques et l'évaluation de programmes en suicidologie. In F. Chagnon et B.L. Mishara (Eds.). *Évaluation de programmes en prévention du suicide.* Sainte-Foy : Presses de l'Université du Québec et Paris : Éditions EDK.

Mishara, B.L., & Tousignant, M. (2004). *Comprendre le suicide*. Montréal : Presses de l'Université de Montréal.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1978). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research.* Washington, D.D.: U.S. Government Printing Office.

National Conference on Youth Suicide. (1985). *Report of the National Conference on Youth Suicide*. Washington: Department of Health and Human Services.

Packman, W.L., & Harris, E.A. (1998). Legal issues and risk management in suicidal patients. In B. Bongar, A.L. Berman, R.W. Maris, M.M. Silverman, E.A. Harris & W.L. Packman (Eds.). *Risk Management with Suicidal Patients.* New York: Guilford Press.

Pardun, J.T. (1998). Good Samaritan laws: a global perspective. *Loyola of Los Angeles International and Comparative Law Journal*, 20(3), 591–613.

Plato. (1955). *Plato's Phaedo*, transl. and comm. R.S. Bluck, Indianapolis: Bobbs-Merrill.

Porkorny, A.D. (1998). Prediction of suicide in psychiatric patients. *Archives of General Psychiatry,* 60 (suppl 2), 70–74.

Prado, C.G. (1998). *The Last Chance, Preemptive Suicide in Advanced Age.* Westport, CN: Prager.

Rubenstein, E. (2004). *Going Beyond Parents and Institutional Review Boards in Protecting Children Involved in Nontherapeutic Research.* San Francisco: Unpublished thesis, Golden Gate University School of Law.

Stack, S. (2000). Media impacts on suicide: A quantitative review of 293 findings. *Social Science Quarterly*, 81(4), 957–971

Stack, S. (2002). Media coverage as a risk factor for suicide. *Injury Prevention*, 8 (suppl IV), iv-30–iv32.

Van Praag, H.M. (2002). Why has the antidepressant era not shown a significant drop in suicide rates? *Crisis,* 23(2), 77–82.

Weisstub, D.N. (1998). The Ethical Parameters of Experimentation. In D.N. Weisstub (Ed.). *Research on Human Subjects: Ethics, Law and Public Policy*. Oxford: Pergamon Press.

WHO. (2002). *World Health Report.* Geneva: World Health Organization.

AUSTEN GARWOOD-GOWERS

CHAPTER 25

THE RIGHT TO BODILY SECURITY VIS-À-VIS THE NEEDS OF OTHERS

1. INTRODUCTION

Bodily freedom has two important dimensions. Firstly, freedom from being forced to do things with one's body and have things done to it. Secondly, freedom from being constrained in what one decides to do with one's body or have done to it. Central to any reasonable definition of a right to bodily security is the protection of the first freedom from direct and intentional invasion and threat of invasion. Legal and ethical norms allow for the restriction of this freedom to protect the individual at issue and the rights of others. However, the idea of restricting it merely to meet the needs of others is more controversial.

Medicine has become an increasingly important lens to view this controversy. Over the last century in particular, there has been a dramatic increase in the value of the human body as a tool to meet general medical ends in fields like medical research and education and also as a direct source of therapy with developments in transplantation and bioetechnology. These changes have been accompanied by dilution of the medical tradition of viewing bodies as predominantly something one does therapy to and only incidentally gets medical benefits from. Sub-optimal and non-therapeutic intervention on the living is now commonplace and cadavers are now used to meet a variety of medical purposes on a mass scale. Problems in meeting "demand" for use of the body have inspired discourse in fields like medical research and transplantation to focus increasingly on whether demand is – or should be – treated as a basis in its own right for making use of people's bodies.

2. LEGAL PROTECTION OF THE RIGHT TO BODILY SECURITY VIS-A-VIS THE NEEDS OF OTHERS

2.1 An International Norm of Absolute Protection?

The response of the international community to atrocities committed by the Nazis and others before and during the Second World War included a plethora of initiatives which were designed to protect the individual from abuse of power by the state. In the light of the fact that doctors had carried out many of the atrocities some of the initiatives were specifically designed to help ensure that medical practice was carried out in a manner consistent with human dignity. The World Medical Association created the *Declaration of Geneva* (1948) *Physicians Oath* and

D.N. Weisstub and G.D. Pintos (eds.), Autonomy and Human Rights in Health Care, 375–398.

International Code of Medical Ethics (1949). Amongst other things, the former require medical professionals to swear treat they will treat the health of their patients as their 'first consideration' and the latter stipulates that '(a)ny act, or advice which could weaken physical or mental resistance of a human being may be used only in his interest.' The Association also built on the principles for ethical conduct of medical experiments on humans that were laid down in the judgments at the Nuremburg Trials (Katz, 1972, pp. 305–306) by creating the *Declaration of Helsinki (1964 as amended most recently in Scotland 2000)* Principle 5 of which states that,

> In medical research on human subjects, considerations related to the well-being of the human subject should take precedence over the interests of science and society.

Meanwhile, the Council of Europe's *Convention for the Protection of Human Rights and Biomedicine* (*CHRB, 1997*) lays down a framework of basic standards for national regulation with respect to intervention in medicine and biology which includes the requirement that:

> The interests and welfare of the human being shall prevail over the sole interest of society or science (Article 2).

However, both the *Declaration* and the *CHRB* have provisions concerning research on the incompetent that appear to be structured in such a way as to permit dilution of protection. Principle 24 of the Declaration states that:

> For a research subject who is legally incompetent, physically or mentally incapable of giving consent or is a legally incompetent minor, the investigator must obtain informed consent from the legally authorized representative in accordance with applicable law. These groups should not be included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.

Principle 26 adds that:

> Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate.

Admittedly, principle 24 talks about the need for the research to be necessary to promote health but this is a reference to the health of the population. This means, for example, that research could be performed on a sufferer of Alzheimer's disease simply because it was necessary to promote the health of Alzheimer's sufferers taken as a whole. In other words, the intervention is not required to be the optimal choice for the individual sufferer subjected to it, indeed it is not even required to benefit him or her at all. The substantive requirement in the first sentence of principle 26 may indirectly temper this problem but it does not solve it.

Meanwhile, Article 17 of the CHRB, entitled 'Protection of persons not able to consent to research,' states that:

> 1. Research on a person without the capacity to consent as stipulated in Article 5 may be undertaken only if all the following conditions are met:
>
> i.) the conditions laid down in Article 16, sub-paragraphs i to iv, are fulfilled;[*]
>
> ii.) the results of the research have the potential to produce real and direct benefit;
>
> iii.) research of comparable effectiveness cannot be carried out on individuals capable of giving consent;
>
> iv.) the necessary authorisation provided for under Article 6 has been given specifically and in writing; and
>
> v.)the person concerned does not object.
>
> 2. Exceptionally and under protective conditions prescribed by law, where the research has not the potential to produce results of direct benefit to the health of the person concerned, such research may be authorised subject to the conditions laid down in paragraph 1, sub-paragraphs i, iii, iv and v above, and to the following additional conditions:
>
> i.)the research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same age category or afflicted with the same disease or disorder or having the same condition;
>
> ii.)the research entails only minimal risk and minimal burden for the individual concerned.

The key provision here is 17(2)(i) which makes it clear that the research does not have to be aimed at (or presumably have the prospect of resulting in) benefit to its subjects if it has a benefit to other persons in the same age category or afflicted with the same disease or disorder or having the same condition. Taken in isolation, Article 17 would even allow researchers to subject an incompetent adult to research that will not benefit him or her at all.

Whilst these provisions appear to dilute protection of the incompetents in order to meet the need for research, there are a number of reasons why they ought to be read down so as not to do so. Firstly, to maintain consistency with the norm of primacy of the individual that is central to both instruments. Admittedly, through Article 26(2), the *CHRB* expressly envisages many of its rights and protective provisions being restricted, including Article 2. However, Article 26(1) only allows such restrictions as are 'prescribed by law and are necessary in a democratic society

---

[*] These conditions relate to their being no alternative of comparable effectiveness to research on humans, the risks incurred by the subject not being disproportionate to the potential benefits of the research, prior approval by the competent body after independent examination of its scientific merit (including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability) and the subjects being informed of their rights and the safeguards prescribed by law for their protection

in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.' Even if meeting a need for research were to be classified as part of protecting public health or, more dubiously, the rights and freedoms of others it is unlikely that it would pass the test of being necessary in a democratic society where it comes at the cost of diluting protection of the individual's bodily security since, as Zilgalvis (2004, p. 168) has noted, '(t)he aim of the convention is to protect human rights and dignity and all its articles must be interpreted in this light.' Nor is it likely to be compatible with Article 8 of the *European Convention on Human Rights* (*ECHR, 1950*). The private life aspect of Article 8(1) has been held to be interfered with even be relatively limited intrusions on bodily security such as compulsory urine testing (*Peters v The Netherlands* (1994) 77A DR 75) and the test for justifying restrictions laid out in Article 8(2) is simply a mirror image of that laid down in Article 26(1) of the CHRB. What is more, to mark out incompetent persons for diluted protection would also appear to be incompatible with the equality of persons ethos that is otherwise promoted in the *Declaration* and *CHRB* and is also central to the *ECHR*. In particular, Principle 8 of the Declaration emphasizes protection of the vulnerable and Articles 1 and 14 of the *CHRB* and *ECHR* respectively emphasis the need not to discriminate in the protection of the rights outlined within them.

2.2 Domestic Provisions

The extent to which domestic provisions protect the right to bodily security vis-à-vis the needs of others has been the subject of some debate. Bioethicist John Harris (1977) has cited, 'control of dangerous drugs, control of road traffic, vaccination, screening tests, blood donation, quarantine for communicable disease, compulsory military service, detention under mental health acts, restriction of sexual activities and professional activities of HIV positive people' (p. 13) as examples of the law recognising what he describes as, 'an obligation (sometimes) to make sacrifices for the community or an entitlement of the community to deny autonomy and violate bodily integrity in the public interest' (p. 12). Barring blood donation, it is true that these are situations in which the law has restricted autonomy and/or violated bodily integrity. However, Harris fails to see that arguments for these restrictions could be made on grounds of paternalism and/or the protection of the rights of others. With the possible exception of compulsory military service, they do not provide compelling evidence that the law violates the right of bodily security in order to meet the needs of others. Another example used by Harris is that of a ship's crew having a legal duty to rescue the passengers and crew of another ship that is in distress. He suggests that the principle of equality,

> reminds us that the passengers on the stricken liner have as good a claim to our protection as any other persons…and that while we are not obliged to afford that protection at all costs, we are obliged to act morally when the costs of so doing are reasonable given the importance of what is at stake (p. 21).

However, the point about this duty is that it is specific to a particular geographic area (the sea). Since people have a choice of whether or not to enter that area they have a choice about whether to be rescuers. The state is acting reasonably by requiring mutual reliance in a dangerous area, but if you don't want to be bound by that you can simply avoid the area.

Calabresi (1991) makes the same mistake as Harris. He cites restrictions on mutilation of our bodies and selling our body parts as examples (p. 12). In fact these restrictions are founded on the idea that we should protect against abuse of the body. However, Calabresi also cites the decision in *Feres v United States*, 340 U.S. 135, 146 (1950) which would appear to be an example of the law condoning need of others based intrusion on the right to bodily security. Here compensation claims of American servicemen who had been given LSD experimentally without their knowledge or consent were rejected on the basis of a principle that serviceman cannot be compensated for injuries that arise out of, or are suffered in the course of activity incident to service. *Feres*, however, would appear to be of more historical significance than anything else. More recently American authority points away from such serf like treatment of servicemen. For example, in *In Re Cincinnati Radiation Litig* 874 F Supp 796 (SD Ohio 1995) the 14th amendment right not to be deprived of life, liberty or property without die process of law was successfully argued in relation to whole body irradiation experiments performed on cancer patients in the United States in the mid-1960s and early 1970s. These experiments were sponsored by the Department of Defence and were designed to acquire information about the after effects of irradiation rather than to benefit the patients who were not properly informed – and in some instances not informed at all – about the nature of the experiment.

English law is equally beginning to stand up to the problems caused by military experiments, not least the sarin experiments that were performed on at least 349 servicemen at the Porton Down biological weapons military base in Wiltshire. One of these servicemen was Mr Maddison who died in 1953 30 minutes after having 200 mg of sarin dripped onto a patch of uniform on his arm. This experiment was conducted in spite of the fact that serviceman James Kelly had suffered near fatal poisoning from a similar incident just nine days earlier. A verdict of death by misadventure handed down by a 1953 coroners hearing was recently quashed in *Re Maddison, Deceased* [2002] EWHC 2567 Admin. A new inquest has recently returned a verdict of unlawful killing (Leighday, 2004). This will pave the way for civil cases on behalf of servicemen affected by the trials (Leighday, 2005) many of whom were allegedly told that they were being tested to find a cure for the common cold.

Red herrings and historical atrocities aside, the domestic picture can still be considered a mixed one. On the one hand common law jurisdictions start from a position of appearing to provide absolute protection. This is most lucidly demonstrated in the American case of *McFall v Shimp* (1978) No. 78-17711. 10 Pa D & C (3d) 90 (Ct Comm Pl, Pa). This case arose out of a situation in which David Shimp had been undertaking bone marrow tests for suitability to donate bone marrow to his cousin Robert McFall, an aplastic anaemia sufferer. Shimp was found to be a match but backed down from undertaking the remaining tests necessary to determine his suitability to donate. McFall petitioned the Alleghany County Court to force Shimp to undertake these remaining tests and, if found suitable, to 'donate.' Giving judgment, Mr Justice Flaherty rejected this argument in powerful terms:

> The common law has consistently held to a rule which provides that one human being is under no legal compulsion to give aid or to take action to save another human being or to rescue. A great deal has been written regarding this rule, which, on the surface, appears to be revolting in a moral sense. Introspection, however, will demonstrate that the rule is founded on the very essence of our free society. Our society, contrary to many others, has as its first principle, the respect for the individual, and that society and government exist to protect the individual from being invaded and hurt by another. … For our law to compel the defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits, and one could not imagine where the line would be drawn…For a society, which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck its sustenance for another member, is revolting to our hard-wrought concepts of jurisprudence. Forcible extraction of living body tissue causes revulsion to the judicial mind. Such would raise the spectre of the swastika and the Inquisition, reminiscent of the horrors this portends (p. 91).

His Honour's observations about many non-common law approaches had already been born out by Feldbrugge's study (1966) which found that many jurisdictions, particularly in continental Europe, impose a legal duty to rescue in the accident, common danger and emergency situation (pp. 655–656). Whilst this duty does not normally extend to being required to expose oneself to 'significant danger' (Price, 2000, p. 234) the fact that it might involve exposure to even some danger clearly makes it an intrusion not just on the freedom of bodily action aspect of the right to bodily security but also the bodily integrity aspect. However, the chances of it being interpreted to allow forced bodily intrusion seem remote. Nonetheless, there are those who have argued, even from a common law perspective, that such intrusion might, on occasion, be legally acceptable. Skegg (1988), for example, has wondered whether the doctrine of necessity might be used to justify a very minimal intrusion that would meet an important need,

> (i)t is just possible to envisage cases in which a court might grant an absolute discharge if criminal proceedings were brought. One such case might be where a patient with a rare blood group will die if his blood is not 'topped up', and the only way of obtaining the blood is to remove it from someone who is unable to consent (p. 117).

Meanwhile, Gerald Dworkin (1978, p. 445) has argued that a "not against interests" standard might be appropriate with respect to medical research on young minors. This standard has no precise meaning. However, invariably it has been used to try and justify trespasses on the incompetent person that cause no or de minimus physical damage irrespective of whether or not they confer a counterveiling benefit *and hence irrespective of whether or not they are in fact against the incompetent person's interests*.

The necessity argument has already come before the English Courts. Notably, counsel for defence in the infamous case of *R v Dudley and Stephens* (1884) 14 QBD 273 tried to use it to justify the actions of sailors who had killed and eaten a cabin boy who had escaped a shipwreck with them on a lifeboat. The survival of the sailors had clearly been in question because they had spent 20 days on the open sea with only two tins of turnips for sustenance. Nonetheless, a specially convened panel of five judges concluded that to allow a defense of necessity here would be to divorce law absolutely from morality. It was not possible, they felt, to judge the comparative values of lives and it was in no way a necessity to kill the weakest, youngest, most unresisting person on the boat as opposed to one of the grown men. In modern terms such a reading of necessity is bolstered by human rights norms that protect the principle of equality of persons, such as Article 14 of the *ECHR*. Even in the UK where Parliament is often said to be sovereign, the Courts are likely to refuse to apply legislation which seriously breaches this principle. In *Oppenheimer v Cattermole* [1976] AC 249 a majority of the House of Lords agreed (obiter) that they would not recognise a Nazi decree depriving Jews of land. As Lord Cross of Chelsea put it,

> …legislation which takes away without compensation from a section of the citizen body singled out on racial grounds all their property on which the State passing the legislation can lay its hands and, in addition, deprives them of their citizenship...constitutes so grave an infringement of human rights that the courts of this country ought to refuse to recognise it as law at all.

The situation in *Dudley* would have posed greater difficulty if, for example, all those in the boat had drawn lots and someone who had been forced to participate in that process had come up with the "short straw" and then been eaten. Here, the principle of equality of persons would be satisfied. However, it is unlikely that the principle of necessity would be. The forced implementation of a scheme that will cost the life of an individual would seem to be unacceptable from a bodily security standpoint even if, in the eyes of some, the scheme can be considered utilitarian. Indeed, even without force a scheme with such consequences would fall foul of public policy restrictions on what can be validly consented to.

The issue of killing to meet another's need recently arose again in the English Courts in *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147. Here the Court of Appeal authorised an NHS Trust to electively "separate" what they described as "conjoined twins" – who were given the pseudonyms Mary and Jodie. Ward LJ laid out the medical facts of the case in some detail (pp. 155–164). Mary was described as having severe medical problems including a heart that was so weak Jodie's heart had to do nearly all the work of pumping the blood around both of them. It was stressed that this would result in Jodie dying within a short space of time. Elective "separation" was the only reliable method of avoiding this outcome (pp. 166–170) but Mary would not survive such an operation. Two of the key questions for the Court were whether this separation could thus be classed as murdering Mary and, if so, could a justification for this be found. Walker LJ concluded that:

> …the proposed operation would not be unlawful. It would involve the positive act of invasive surgery and Mary's death would be foreseen as an inevitable consequence of an operation which was intended, and is necessary, to save Jodie's life. But Mary's death would not be the purpose or intention of the surgery, and she would because tragically, her body, on its own, is not and never has been viable (p.259)…

In the last part of this statement his Lordship seems almost to be implying that the separation would not be murder because the surgery would not cause Mary's death, a clearly incorrect view which was rejected by Lord Justices Ward (p. 190) and Brooke (p. 205). Contrastingly, the first part of the statement seems to suggest that the *mens rea* for murder – i.e. intent – would not be present. In English law, murder is deemed to have been intended not only when death was purposely brought about but also, as a general rule, where it is foreseen as a virtually certain result of an action (*Reg v Woollin* [1999] 1 AC 82). Evidently, the operation of separation could be seen as murder on this basis. However, his Lordship seems to have been suggesting that it could fit into the exceptional category of cases where foresight is insufficient.

Lord Justice's Ward and Brooke preferred to rely on defences, respectively using quasi self-defense (p. 204) and necessity (p. 240). Whilst the Court stressed, for policy reasons, that its decision was case specific case, the judgments seem to clearly point toward a broader principle. Namely, that it is acceptable under the criminal law for one person to be defended to the point of killing against a threat posed to their life by another – even if that other is "innocent" of any culpability for the fact that the threat exists. Such a conclusion is not offensive from the point of view of a right to bodily security discourse. However, this is not to say the Court was right to come to the decision it did. On the contrary the following analysis suggests that it misconstrued identity issues in such a way as to end up authorizing an act that was barely more defensible than the actions of the hungry sailors in *Dudley and Stephens.*

Whilst the term conjoinment suggests a fusion of two things, the Court of Appeal accepted that what it was actually dealing with was the product of a single embryo never fully achieving the separation into two embryos that it was encoded for. As Brooke LJ stated the situation had arisen,

> from an incomplete division of the inner cell mass about 15 to 16 days after the egg is fertilised, and about seven days after what is called monozygotic twinning is said to occur. The incomplete division of the embryo appears to be associated with a process that inhibits the complete differentiation of the various organ systems (pp. 205–206).

In spite of this, the Court proceeded as if it were dealing with two persons. Whilst this may be true psychically in as much as there appeared to be two souls, it was hardly true physically. What confronted the Court physically was a single whole. This whole may have had nearly twice the 'normal' level of parts for a single body but it was not credibly divisible into two, not least because there was no objective line to point to and say 'here is where one starts and the other ends.' If the Court had taken note of this it would have realized that the bodily threat came from within what belonged to or with both souls. It would then have treated "separation" not as act of defending one soul against the body of another soul but as an act which fatally disregarded the co-inhabitational rights of one soul in order to have the body functioning in a manner that more proficiently met the inhabitational needs of the other.

If the outcome in *Re A* was ultimately a triumph of needs over rights it was only unwittingly so. The common law continues to be aimed at respecting people when making decisions on their behalf of a person, whether it is the best interests test that is adopted or some other approach such as substituted judgment (see further Tomossy and Weisstub, 1997). The best interests test has effectively been enshrined in English law by section 1 of the Children Act 1989 in relation to minors being decided for and by section 1(5) of the Mental Capacity Act 2005 in relation to incompetent adults. Lord Reid may have stated in *S v S, W v Official Solicitor* [1970] 3 All ER 107, 111–112 that it was permissible to use a not against interests test in relation to blood testing minors to determine their paternity but Dworkin was wrong to use this as authority for the not against interests test being applicable in the research context. Cases such as *S v S, Re X (A Minor)* [1975] 1 All ER 697 and *Re S (A Child) (Identification: Restrictions on Publication)* [2004] UKHL 47 may have authorized departure from best interests protection of the minor but only where necessary to do so to take proper account of the rights of others not merely to take into account their needs. The real threat of needs of others based intrusion under the law comes in relation to incompetent adults. Certain provisions of the Mental Capacity Act 2005, most notably section 31(5), appear to manifest that threat with respect to intrusive research on the incompetent adult. However, as with parallel provisions in the *Declaration of Helsinki* and *CHRB* there are a number of reasons why these provisions are likely to be read down. These reasons include: The fact that all acts performed and decisions taken in relation to the incompetent adult are supposed to be in the best interests of the incompetent adult by virtue of section 1(5) of the Act; the fact that section 33(3) specifically stresses that the interests of the incompetent adult must be given primacy in the intrusive research context; and the fact that any other approach is likely to be incompatible with the European Convention on Human Rights (particularly Article 8, potentially Article 3 and Article 14 in conjunction with one or both) and ultimately even the *Declaration of Helsinki* and *CHRB* themselves.

Much more problematic are laws restricting abortion. These can be viewed as intruding on the right to bodily security of women to meet the needs of embryos/fetuses. This problem can be illustratred by way of Judith Jarvis Thomson's unconscious violinist scenario:

> You wake up in the morning and find yourself back to back in bed with an unconscious violinist. A famous unconscious violinist. He has been found to have a fatal kidney ailment, and the society of Music Lovers has canvassed all the available medical records and found that you alone have the right blood type to help. They have therefore kidnapped you, and last night the violinist's circulatory system was plugged into yours, so that your kidneys can be used to extract poisons from his blood as well as your own. The director of the hospital now tells you: Look, we're sorry the Society of Music Lovers did this to you – we would never have permitted it if we had known. But still, they did it, and the violinist now is plugged into you. To unplug you would be to kill him. But never mind, it's only for nine months. By then he will have recovered from his ailment, and can safely be unplugged from you (1971, pp. 48–49).

If one concedes that the law should not violate one person's right to bodily security merely to meet another person's need, the only basis on which to ground restrictions on abortion is to argue that women voluntarily assume a duty to carry an embryo/fetus. However, whether such a duty can be properly said to exist is open to question. Furthermore, if it does, there is no obvious basis on which to argue that it extends to situations in which a woman has played no voluntary role in conception.

Nonetheless, most jurisdictions fail to specifically exclude women who have conceived via rape from their systems of abortion control.

Some legal approaches to control of legitimately extracted body materials from the living also raise a problem. Materials extracted consensually or otherwise legitimately in the medical context are frequently treated by the extractors as effectively abandoned and therefore capable of being put to other uses. Such an approach was supported in *Moore v Regents of University of California* 793 Pd 479 (1990). The key facts of this case were that the plaintiff had hairy cell leukemia and as part of his treatment had had his spleen along with some blood, bone marrow aspirate and other bodily substances removed. Unknown to him, but known to his physician, these materials were of a great commercial value. They were subsequently used in research by that physician and a researcher. Material derived from his T-lymphocytes was used by them to establish a cell-line which they obtained a patent for. They were subsequently able to obtain a variety of financial benefits on the back of this. The plaintiff argued conversion along with a large variety of other causes of action. However, for a variety of unconvincing reasons the Supreme Court rejected his arguments. The key point about the case for immediate purposes is not the specific nature of these reasons so much as the fact that the outcome amounts to allowing legitimately removed body materials to be treated much in the same way as an old sofa left on a public pavement in front of a house. In other words, no recognition is given to the fact that the body is such an intimate and private aspect of oneself that when one has parts of it removed it might be legitimate to consider that one has implicitly consented to it being stored for one's benefit or incinerated but not to it being utilised to the ends of others (see further Matthews, 1995). Section 44 of the United Kingdom's *Human Tissue Act 2004* is an example of legislation embodying a *Moore* type approach. The Government had initially committed itself to a consent based approach in this area but this was successively watered down in response to pressure from vested interest groups including the Academy of Medical Sciences and the Association of Research Charities (Price, 2005, pp. 803–804).

A not dissimilar problem has recently arisen in the context of police retaining fingerprints and samples from persons who were suspected of having committed relevant offences but were subsequently acquitted or had their charge discontinued. In *R v. Chief Constable of South Yorkshire Police (Respondent) ex parte LS (by his mother and litigation friend JB) (FC) (Appellant) Regina v. Chief Constable of South Yorkshire Police (Respondent) ex parte Marper (FC)(Appellant) Consolidated Appeals* [2004] UKHL 39 the House of Lords (Lords Steyn, Rodger, Carswell, Brown and Baroness Hale) unanimously rejected the argument that such retention was incompatible with Articles 8 and 14 of the *ECHR*. To a certain extent retention in relation to this group can be justified in as much as there position is not the same as that of the public at large. Lord Steyn puts this point in the following terms:

> Until the coming into effect on 11 May 2001 of section 82 of the Criminal Justice and Police Act 2001, the retention by the police of such fingerprints and samples was unlawful under section 64 of the Police and Criminal Evidence Act 1984 (PACE). There was public disquiet that this rule sometimes enabled defendants who had in all likelihood committed grave crimes to walk free (para. 5).

Putting it as high as likelihood is perhaps going too far but there is certainly a sense in which those who are taken all the way through the prosecution process to the point of charge or trial will in many instances have been reasonably suspected and that it could accordingly be argued that retention of fingerprints and samples is justified by reference to the rights of the public at large to defend themselves against possible future criminal activity. However, one of the disturbing features of the case was that no attempt was made to make exceptions for those to whom reasonable suspicion can no longer be deemed to apply, i.e. because evidence pertaining to that suspicion has now been wholly discredited. Another disturbing feature was that their Lordships deemed by a four to one majority (Baroness Hale dissenting) that there was no interference with the Article 8(1) right to private life in the first place.

Also typically problematic from a right to bodily security perspective are laws pertaining to extraction, storage and use of human body materials after death for medical purposes. Most such laws give room for at least some of the deceased's materials to be extracted, stored and used without him or her having consented to this before death. The laws in this area which describe themselves as being founded on the principle of consent or 'opt-in' or 'contract in' often actually treat authorisation by the next of kin as sufficient in the absence of evidence that the now deceased had objected whilst alive. For example, section 4 of Germany's Transplant Act of 1997 (Federal Law Gazette, Part 1, No 74, 11th Nov 1997, 2631) states that in the absence of their being written evidence of consent or objection by the now deceased, the next of kin is to be asked if they knew of any objection by him or her and if the answer is no they are asked to make the decision on whether to go ahead, albeit in a manner which respects the presumed wishes of the now deceased. As Price (2000, p. 93) notes section 2 of Venezuela's 1994 Resolution implementing its 1992 law has an almost identical provision and similar provisions exist within Algeria, Sri Lanka and Turkey. English law will also adopt this approach once section 3 of the Human Tissue Act 2004 comes into force some time on or after April 2006. Many jurisdictions go further by having what are typically opting-out, contracting-out or presumed consent systems. These systems can take 'weaker' and 'stronger' forms. Both allow extraction, storage and use of materials without consent but the former typically only do so where reasonable enquiry turns up no evidence that either the deceased or a surviving spouse or relative has objected to this and the latter typically do so even where such enquiry does turn up an objection by a surviving spouse or relative provided that there is not evidence, or clear evidence, of the deceased him or herself having objected. Some jurisdictions have an element of absolute compulsion in relation to the way they treat the body after death. Despite official denial, it is evident that Chinese authorities sanction the routine harvesting of organs of executed prisoners (Rothman, 1997, p. 39). So it seems do a few other countries including the Syrian Arab Republic under section 3 of its Law of 23 August 1972.

Clearly the potential for unwanted bodily intrusion within a system that does not require actual consent from the now deceased is particularly high. Due to time constraints for the effective use of cadaveric body materials for transplantation, some such systems are rather limited in terms of the level of enquiry into possible objection that they require. In some countries problems with the level of enquiry are compounded by the lack of a reliable and easily accessible mechanism on which to record objections, such as a national database. Furthermore, even when such a mechanism does exist it is prone to being used as a propaganda tool to support a position that deviates from actual consent of the deceased. In France, for example, the act of setting up of the Registre National des Refus, under the 1994 Lois de Bioéthique was not purely conceived of as a means to ensure that voiced objections were recorded but also to support the argument that those who had not voiced objection could be treated as donors (Nowenstein, 2005). To their credit most of the French population do not accept this line of reasoning as valid (Carvais and Hermitte, 2000). Its obvious flaw is that the term 'donor' actually implies that one has made a positive choice to offer something. In this context it means that one has actually consented to the specific use or uses of a specific body material or range of body materials. In this light, it is not clear why the mere consent of the deceased's next of kin should ever be deemed sufficient to classify the deceased as a 'donor,' unless perhaps it is based on knowledge of and adherence too the deceased's wishes. Still less is it appropriate to call the deceased a 'donor' when no-one at all has consented. Equally, to pretend by using the term 'presumed consent' that an absence of objection constitutes consent is somewhat deceitful. Consent 'is either implicit or explicit or it doesn't exist at all' (Garwood-Gowers, 2001, p. 327) and no matter how customary or popular a certain practice is, one cannot imply consent to it simply because someone has failed to object (Price, 2003, p. 15). The implication that a person has consented to something must be based on some form of positive assent on their part in the light of an awareness of the broad nature of what is involved. In practice, for the most part, it will be difficult to find that the deceased has given consent to use in the absence of them having explicitly stated as much whilst alive.

Although absence of objection systems do not protect against unwanted intrusion, Cohen (1992) has argued that they better protect the autonomy of the now deceased because in the absence of objection use is more likely to be consistent with the wishes of the now deceased than non-use. More optimistic studies tend to show that around seventy per cent are willing to donate after death (see further Garwood-Gowers, 1999, p. 24). Nonetheless, Cohen's argument is open to statistical challenge because a portion of this seventy per cent are people who will indicate their wishes to next of kin, on a donor card or in some other way. It is only the proportion who do not do so that are relevant for comparison statistically. What is more Cohen's approach is based on a distorted notion of autonomy. Above all autonomy is about protecting people from unwanted intrusions. It is preposterous to suggest that it is autonomy enhancing to give one set of people what they may have wanted but didn't ask for at the cost of the right to bodily security of another set. This point has been made forcefully be Veatch (1995) in relation to whole body perfusion performed on the cadaver for the purpose of temporary organ preservation:

> Autonomy in no way gives one a right to be a subject of a medical procedure, an experiment or organ procurement…The only relevance of autonomy to perfusion is that any perfusion prior to consent violates the individual's autonomy rights (p. 201).

Indeed, Veatch goes on quite rightly to state that:

> This is true not only for the half of the population that would refuse to consent to donation if asked, but also the group who would consent if asked but who would object to invasion of the body without being asked (p. 201).

3. AN ETHICAL CASE FOR RELATIVE PROTECTION OF THE RIGHT TO BODILY SECURITY VIS-A-VIS THE NEEDS OF OTHERS?

3.1 Introduction

Some of the proposals for relative protection of the right to bodily security vis-à-vis the needs of others relate to a specific class of person, such as the incompetent. Not surprisingly, the 'not against interests test' has sometimes been put forward as appropriate with respect to such interventions as non-therapeutic intrusive research on incompetent persons (e.g. Kennedy, 1998, paras 1340–1345) or more specifically incompetent adults (e.g. Medical Research Council, 1991; Gunn et al., 2000 at 66). The Law Commission's approach to reforming adult mental capacity law included the recommendation in its Report *Mental Capacity* (1995) that:

> Research which is unlikely to benefit a participant, or whose benefit is likely to be long delayed, should be lawful in relation to a person without capacity to consent if 1) the research is into an incapacitating condition with which the participant is or may be affected and 2) certain statutory procedures are complied with (para. 6.31).

The procedures referred to were to include approval of the research by a Mental Incapacity Research Committee which, to paraphrase, would, amongst other things, have to satisfy itself that the research:

> a.) is desirable in order to provide knowledge of the causes or treatment of, or of the care of persons affected by, mental disability;
>
> b.) has an object which cannot be effectively achieved without the participation of persons who are or may be without capacity to consent; *and*
>
> c.) will not expose such a person participating in the research to more than negligible risk and that what is done in relation to such a person for the purposes of the research will not be unduly invasive or restrictive and will not unduly interfere with his freedom of action or privacy (para. 6.34).

These may be strong safeguards but they do allow for some research interventions that are inconsistent with best interests. In relation to non-research situations the Commission recommended that the Secretary of State should be able, after consultation, and subject to an affirmative resolution by each House of Parliament, to make an order providing for the carrying out of a procedure on an adult person lacking capacity to consent to it where the procedure, although not carried out for the benefit of that person, would not cause him or her significant harm and would be of significant benefit to others (para. 6.26). This could apply to some forms of living donor transplantation, such as blood donation and perhaps even bone marrow donation. It would also apply to at least some of the various procedures that can be performed on insensiate dying persons to facilitate the use of their organs after death. One could envisage, for example, it being used to justify taking a blood sample for tissue typing and whole body perfusion to chill organs, though perhaps not necessarily procedures like elective ventilation which might slow the timing of death, let alone procedures like administration of heparin which might speed it up (see further Garwood-Gowers, 2005, pp. 201–203).

Interestingly, when the process of creating adult mental capacity legislation began in earnest with the Secretary of State for Constitutional Affairs presenting the Draft Mental Incapacity Bill to Parliament in June 2002, there was no hint that the Commission's ideas with respect to non-therapeutic interventions were being seriously considered. However, the Government was persuaded by the House of Commons, House of Lords Joint Committee Report on the Draft Bill (2003, para. 275–288) that there was a case in the research context for trading down from protecting the best interests of the incompetent adult. The Joint Committee itself appeared to have taken this view not least because it was influenced by excessively narrow conceptions of what research was possible on an incompetent adult under a best interests test (para. 279). However, by the time reform in this field had culminated in The Mental Capacity Act 2005 even this idea had lost influence. As earlier noted, its spirit may have been embodied in some of the Act's provisions, including section 31(5) but it was effectively undermined by others, such as section 33(3) and section 1(5). The upshot is the Act cannot reasonably be interpreted as allowing deviation from protection of the bodily security interests of the incompetent adult in the intrusive research context.

Some commentators have gone further, particularly in relation to transplantation, by suggesting that everyone might have protection of their bodily security diluted in order to meet the needs of others. Harris (1975) once put forward the idea of a "survival lottery" under which everyone would be entered into a regular draw and whoever had their number randomly selected would be forced to give up certain body materials to save the lives of others. Not one to take half measures, Harris suggested that the conscription could be extended to forcing those randomly selected to give up organs that were necessary to maintain their own life so as to maximize the utility benefits to others. A few years later Huffman (1979) responded with disapproval to the judgment in *McFall*, and suggested that failure to give body materials to those in need should lead to criminal charges – including manslaughter charges where an "unrescued" person died.

Meanwhile most discourse pertaining to medical uses of the cadaver adopts a position other than one oriented around the consent of the now deceased person, justifying this partly by reference to the perceived need to meet various medical needs – particularly the need to procure more organs for transplantation. However, equally it is self-evident that any system of procurement except one of total conscription is also reliant on public support and any system that is significantly out of accord with the views of the public risks being undermined. The adverse effect that recent organ retention and use scandals initially had on cadaveric organ procurement in the United Kingdom is a case in point (see further Price, 2003). These scandals did not extinguish calls for English law to be moved toward a stronger opt-out system but not surprisingly the Government ended up moving in the opposite direction to a weak opting-in system.

One way of compromising between opt-in and opt-out approaches would be to compel people to respond to and return a questionnaire about their wishes with respect to use of their body materials after death. Pennings (1995) has suggested that although people would be compelled to fill in the form they could be given the option of saying "cannot answer" as well as "no" or "yes" and that only in the event of a yes answer would their materials be taken. Equally, he has suggested that the will of the deceased should be treated as final when such a system is in operation because,

> allowing the next-of-kin to object would come down to treating a person's altruistic desires as suspect, as something that has to be corroborated by others.

However, whilst such a system avoids unwanted bodily intrusion it invades freedom from forced bodily action. Even if the forced action is only putting pen to paper it still amounts to violating the right to bodily security and it is doing so to meet a need. One solution might be to "tweak" the system to eliminate the compulsory element. Questions about wishes for use of one's body could become, for example, voluntary sections on census forms though the fear here would be that people might be prone to mistaking them to be compulsory.

3.2 Arguments for Reform

Justice arguments

At one end of the spectrum of views about distributive justice, is the idea that one should give what one can and be given what one needs. At the other end is the view that what one gets and what one gives should be matched. Most states have adopted a hybrid approach in practice whereby people are allowed to keep much of the rewards for their work but have taxation levied on them partly by reference to their ability to pay. These same people are guaranteed access to certain essential resources irrespective of past or present contribution on their part. Those resources tend to include healthcare provision of a reasonable standard or at least a standard that is reasonable relative to the resources that the state in question has. One of the international standards that reflects this is Article 3 of *The Convention on Human Rights and Biomedicine*. It states that parties,

> taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to appropriate healthcare of appropriate quality.

However, despite the context of need and resource, the term 'equitable' may be a sufficiently vague notion of fairness or justice to enable contribution to be considered relevant to it. The main contribution is likely to be money. However, alternatives are available. For example, in the field of organ transplantation, it could be linked to whether one has registered willingness to become an organ donor. Rupert Jarvis's modest version of this where those who have registered willingness should be given priority on the organ transplant waiting list (Jarvis, 1995). Such a proposal might increase the pot of available organs and thereby decrease waiting lists overall. However, even those who consider Jarvis's idea well intentioned might reject it on the basis that it would make it difficult to defend the line against non-clinical factors influencing access on a much wider basis (Gillon, 1995, p. 196). Such a defence is widely considered to be necessary, not least because the function of judging contribution is seen as inconsistent with the maintenance of a bond of trust between healthcare services and professionals on the one side and patients and the public at large on the other.

One way of not taking into account non-clinical factors and yet still gaining greater use of the body is to *force* contribution from property and/or the body itself. Two types of justice based argument have been used to endorse force. The first is that by not forcing people to contribute, we allow non-contributors to free-ride off the benefits that contributors have helped to create. The second is specific to the body; it declares that claims on it and its parts should be ranked in accordance with need. A necessary foundation for this second argument is that a person does not inherently have a right to use their body or its parts to any degree greater than anyone else.

The first argument has been used in the context of medical research. Gunn, Wong, Clare and Holland (2000) suggest that,

> If one wishes to gain the benefit of medical research, one has the obligation to offer oneself for participation. Otherwise, the person gaining the benefit of the research is a mere parasite on society, taking only the advantages and undertaking no risks (p. 63).

The focus of their article was non-therapeutic intervention on incompetent adults where they felt that the 'best interests' tests should be abandoned in favor of a diluted method of protection of bodily security, partly to avoid this group getting benefits without participating. They drew on an earlier article on the use of incompetents adults in research written by Harris (1997) who suggested that,

> It is not plausible to believe that the costs of acting morally fall only on those competent to consent. So long as we ensure that such costs do not fall *more heavily* on those not competent to consent than on others I see no sound argument for exempting them from the demands of morality. They may not be *accountable* in law, if they do wrong, but there is no reason to ensure that they do wrong by exempting them from their moral obligations (p. 12).

He later adds that if we can pursue research without the use of incompetent adults so much the better, but if the current position:

> jeopardises our capacity to pursue well founded research then perhaps we should remember that free-riding is not an attractive principle; nor is it a moral principle. We should not … assume that those incompetent to consent would wish to be free-riders, nor that they be excluded from discharging an obligation of good citizenship which we all share (p. 13).

Gunn et al., continue by emphasising that the effect of limited participation by incompetent adults as a class of person can be more damaging to them than the limited participation of another class would be to itself. This is because the ability to generalize research outcomes to them without their participation can be limited

(p. 63) and because they will not be involved in research which is largely or wholly for their own benefit as a group (p. 61). They go on to suggest that by facilitating participation a change in the law (i.e. abandoning the 'best interests' approach) would be,

> consistent with principles of normalisation and social inclusion. It challenges stereotypes that incompetent adults are a drain on society (p. 63).

These views are seemingly predicated on overly restrictive conceptions of English law (Garwood-Gowers, 2005, p. 209). Nonetheless, even though the law does not preclude the incompetent adult participation in non-therapeutic research it limits it to a point where they are much less likely to become participants than competent adults and yet are still equally open to share in the fruits of research. However, can this be used as a legitimate basis to argue for reform?

Harris considers the current position to be contrary to the principle of equality of persons. However, having defined equality as the idea 'that each person is entitled to the same concern, respect and protection of society as is accorded to any other person in the community' (1997, p. 12), he hoists himself onto his own petard by stating in a subsequent article that respect involves not just respect for the choices of those competent to make them *but also respect for the best interests or welfare of those who are not* (2002, p. 529) (*ital.* added).

Under Harris's proposal the law will become discriminatory; it will allow researchers to subject incompetent persons to interventions that are not in their best interests whilst leaving competent persons free to refuse such interventions. Giving incompetent persons the choice of whether or not to participate would place them in a *formally* equivalent position as that of competent persons but would *practically* discriminate against them by leaving them in a position to make decisions that, unlike competent persons, they were by definition incapable of making. The current position does not favor incompetents by allowing competents to participate in interventions that may not be in their best interests. Rather, it simply gives competent persons the wide scope to express their will that the right to self-determination warrants. The law in most jurisdictions is careful to ensure that this does not descend into abuse of the competent; public policy restrictions on what can be consented to being likely to ensure both that there are reasonable upper limits to the level of harm and risk that (s)he may be subjected to and a reasonable balance between the harms and risks that are involved in a prospective intervention and its prospective individual and/or community benefits.

The discrimination inherent in Harris's proposal cannot be justified by reference to the goal of seeking equal contribution. He is not complaining about an individual not making an equal contribution, but of a group not doing so. To give a group of individuals less protection than another group is arbitrary with reference to the individuals that make up each group. It would be arbitrary, for example, if Harris himself were to get less protection simply because it was found that his work colleagues at Manchester University had, taken as a whole, underperformed. This might be a light hearted example but let us take one that will more fully bring home the implications of such arbitrariness. What, would we think of rounding up Jews and doing compulsory experiments on them if they, taken as a whole class, were found not to be contributing as much to medical research as other racial groups? Could we seriously suggest that doing this would have benefits in terms of normalization and social inclusion?

Surely groups must be treated equally and free-riding is only a relevant issue when judged in terms of the contribution of individuals vis-à-vis each other. Even here the goal of avoiding free-riding can only be used to justify not giving benefits to those who have not contributed. In using inadequate contribution to restrict the right to bodily security we are actually saying that people should be forced to participate in a system even if they do not want the benefits and hence cannot be described as freeloaders.

The remaining justice argument is that bodies should be distributed in accordance with needs for them. Calabresi (1991) toys with this Marxist ideal in exclaiming that,

> if you are talking about fairness, I really do not understand why the fact that I have inherited good kidneys, or good bone marrow, or good brains, or indeed inherited a good environment, gives me more rights than the person who has inherited bad ones. I am not sure that a person deserves inherited desirable body parts any more than he or she deserves inherited wealth. I might even think the opposite, because with inherited wealth someone else worked so that the person would inherit. The inheritance of body parts, on the other hand, is entirely a matter of luck (p. 12).

This view is based on a very materialistic notion of what it means to be a human. It excludes the possibility that every person has a physical body that may, at least in part, reflect what they need to encourage their spiritual development. Even if it was the case that bodily advantages are purely a matter of luck, there are obvious reasons – both utilitarian and deontological – to suggest that the body is too private a sphere to be invaded simply to fulfill the needs of others.

Utilitarianism

Bentham's version of utilitarianism was that the rightness or wrongness of actions can be judged by their consequences in terms of producing pleasure or pain. He thought that society should be organized in such a way as to produce the greatest happiness for the greatest number of people. John Stuart Mill's approach recognized that protecting liberty was important for the maximization of happiness, particularly in more developed societies. In *On Liberty* he made the famous proposition of general principle that,

> The sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. These are good reasons for remonstrating with him…but not for compelling him, or visiting him with any evil in case he do otherwise. To justify that, the conduct from which it is desired to deter him, must be calculated to produce evil to someone else. The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his

> independence is, of course absolute. Over himself, over his own body and mind, the individual is sovereign (1998, p. 14).

However, being a utilitarian, he was ultimately prepared to see the protection of liberty dispensed with where it did not serve general happiness or well-being. On this basis he suggested that people should be legally obligated;

> to perform certain acts of individual beneficence, such as saving a fellow creature's life, or interposing to protect the defenseless against ill-usage…there are often good reasons for not holding him to the responsibility; but these reasons must arise from the special expediencies of the case: either because it is a kind of case in which he is on the whole likely to act better, when left to his own discretion, than when controlled in any way in which society have it in their power to control him; or because the attempt to exercise control would produce other evils, greater than those it would prevent (1998, p. 14).

Meanwhile, Peter Singer (1972) has used utilitarian thinking to suggest that when it comes to property we should give to relieve the suffering of others up to the point where this can be done without an even greater suffering to ourselves. What if this thinking were applied to using the body? Society would have considerable scope to meet need by using consciously aware people and complete scope to meet need via use of those it deemed to be in a permanently vegetative state or dead and thus unable to experience suffering.

> However, is utilitarianism an appropriate theory? Individuals can only be happy when they treat themselves and others as ends in their own right. Hence, for those individuals to subjugate themselves and others, and be subjugated to a wider end of collective happiness, undermines the very goal of collective happiness itself; utilitarianism must necessarily implode in on itself.

Utility arguments within an approach recognising several ends

A number of thinkers, whilst not necessarily being committed to utilitarianism, do argue that the usefulness of meeting a need could justify some invasions of the right to bodily security. In addition to his justice argument for such invasion, Harris mentions the usefulness, for example, of a survival lottery. Calabresi (1991) adds to his justice argument "that body parts belong to those who need them" the utility argument that if "we focus on society and its values in a communitarian way, this in turn might lead us to think of all of society as one family" (p16). Meanwhile most of those advocating diluted protection of bodily security in relation to incompetent persons do not specifically endorse utilitarianism, but emphasise the benefits of participation for society as if this was itself a justification for dilution.

3.3 A critique of Views That the Right to Bodily Security Should be Treated as Relative Vis-a-Vis the Needs of Others

Underestimation of what needs can be met without diluting protection

Underestimation of what needs can be met without diluting protection has occurred in several ways. One of these is that the best interests test has been construed too narrowly with respect to interventions on the incompetent that have the capacity to benefit others. In particular there have been tendencies to:

1. Wrongly suggest that whether or not an intervention is in the best interests of the incompetent is dependent on whether the purpose of the person undertaking it is benefit to the incompetent; *and*
2. Equate the term therapeutic with best interests and yet at the same time to label interventions which have the capacity to bring indirect benefit to the incompetent – such as non-treatment based research, genetic testing for the benefit of members of one's family and elective ventilation – as non-therapeutic with the consequence that the issue of whether the indirect benefits they can bring might be sufficient to make them in the best interests of the incompetent on occasion is not assessed (see further Garwood-Gowers, 2005, pp. 197–201).

These errors have particularly had a deleterious effect on debate and reform proposals in the United Kingdom (Garwood-Gowers, 2005, pp. 197–201).

It may also be that we could improve medicine whilst lessening the reliance on the use of the body and body materials. That reliance may be partially attributable to Western states tending to adopt an extremely mechanistic and reductionistic approach to medicine which has been heavily criticized both in terms of its empirically observable effects (see particularly Illich, 1977) and in terms of its failure to properly account for over a century of quantam thinking in the physical and other fields of science upon which it purports to be based.

A greater emphasis on health promotion and holistic solutions to medical problems may produce better health care at a cheaper price whilst reducing emphasis on the areas of biotechnological medicine that necessitate the use of body materials. Furthermore, a juster global approach to property and trade combined with a greater awareness of the value of living compassionately would lead us to more rigorously question the relative value of developing and using expensive forms of biotechnology. Making greater use of natural medicine might not reduce the level of experimental research using human subjects, but it would change the impact of that research in the sense that the subjects would be exposed to natural substances which, if carefully chosen and used, may have no adverse effects, whereas through the very fact of being synthetic, synthetic substances do.

A failure to examine the adverse effects of invading the right to bodily security to meet others needs

When it was discovered that several hospitals in the United Kingdom had failed to comply with the checking for objection requirements laid down in section 1 of the *Human Tissue Act* 1961 there was considerable public outrage at what was perceived to widespread disregard for ethics as law (Rodgers, 2003). As well as being reprehensible in their own right these breaches generated follow on problems. The Government ended up spending a great deal of time and resource both directly and indirectly such as through setting up and funding the Retained Organs

Commission to listen to public complaints and take appropriate action, including overseeing the return of wrongly retained materials where appropriate. In what was probably no coincidence, rates of cadaveric organ procurement were 10% lower in the first half of 2002 than they had been in 2001 (UKTSSA). What is also clear is that the problems could not have been wholly avoided by adopting a strong rather than weak opt-out system in the first place. Countries that have a strong system have often reverted to a weak system in practice – France being the classic example (Nowenstein, 2005). Evidently this is because the public do not usually agree with strong systems opt. Perhaps the underlying message in all this is that it is by individuals *choosing* rather than being forced to act in service to humanity that a familial sense of mutual responsibility and support is fostered.

Failing to recognise that the right to bodily security is an inalienable right and is an absolute one vis-à-vis the needs of others All of the arguments for treating the right to bodily security as relative vis-à-vis need fail to examine the counter argument that it is by its very nature an absolute one vis-à-vis the needs of other. To address this counter-argument properly one must return to the most fundamental of philosophical questions; what is our purpose for being here? In response to this it may be suggested through an uncreated creator the whole of reality is imbued with a holistic tendency toward growth. Far from there being a conflict between the interests of different parts of reality, the true interest of all parts is to grow and the growth of each one promotes the growth of others and the whole itself. As each part develops it tends to gain more conscious awareness of its role and is thus able to more consciously develop itself in a manner consistent with growth. Translated more specifically into human terms this could be seen as a process of human beings co-operating with their intrinsic tendency toward "self-actualisation," "self-realisation" or "self-integration" (see particularly Maslow, 1976; Rogers, 1978).

This process includes developing a way of being that goes beyond the misperception that it is to one's benefit to obtain something at the cost of abusing another. Or, to put this positively, moving toward an understanding that what is truly in one's interests is to be in a manner consistent with and enhancing of, the well-being of others and reality as a whole. The role of the body in helping one bring about growth is to be valued and respected. In Lockean terms it is often said that we have a God given right to property in our person (Laslett, 1960, pp. 222–223). This is not a right to treat it as what it is not, i.e. a commodity, but at least a right that exists to the extent that is necessary to protect our 'God given' right and duty to pursue growth. That would seem to imply a general right of bodily security limitable only by reference to what is necessary to proportionately protect the fundamental rights of others and, where the person is not capable of deciding for themselves, by reference to proper external conceptions of their interests. To try and justify intrusion in other terms is to promote the very antithesis of respect for the individual in the bodily context, i.e. slavery. What is more, protecting the interests of incompetent persons must not become a basis on which to subject them to bodily intrusions that will benefit others simply on the basis that they will benefit from being altruistic. There are ample methods by which those lacking capacity can be encouraged and, in some cases, even directed to help others without intruding on something as fundamental and private as their body.

4. CONCLUSION

Much of the discourse in this field has come to view it as being impossible to meet the growing needs for bodies and body materials in a manner that treats their "owners" as having absolute rights over them vis-à-vis those needs. This has undoubtedly helped to generate an increased focus on concepts of ethics that either deny the idea of rights over the body altogether or treat these rights as relative to the needs of others. The former include utilitarianism which irredeemably "collapses in on itself" and Calabresi's notion of justice which even he himself rejects in favour of Kantian libertarianism.[1] The latter, pose a greater threat because they appeal to people's sense of wanting to give credit to both sides of the "ideological divide" by providing a compromise. The compromise looks all the more appealing when it is accompanied by an element of sacrifice (we only propose to invade the body in ways that cause no or little physical detriment and only to supply the most important or desperate needs). However, once one classifies the invasion of bodily ownership as slavery, these arguments start to look like attempted justifications of limited forms of slavery which of course are very much *still* forms of slavery.

As to the law, in democratic and some non democratic systems, the living are free from having things done to their body to meet the needs of others. However, in many jurisdictions of both type they are not free from being forced to do things with their body to meet those needs in the form of a general duty to rescue. Although the latter is less invasive in a privacy sense than the former it is still contrary to treating a person as possessing the limited form of property in their person that it has earlier been proposed that they intrinsically have.

So too are needs of others based interferences in a person's control over what happens to their body after death. Most of the public outcry in recent organ retention scandals in the United Kingdom was not over the fact that such control had not even been respected to the extent required by law but over the fact that many of the "victims" were children whose parents were offended that they had been denied control. The Westminster Government's reform proposals have escaped with not fully respecting the right of living to determine what happens to their body after death because almost no-one has been vociferous on this topic. This may be because some people are unconcerned about interferences that are not, by nature of the state they will be in, physically detrimental. It may also be because there is guilt about putting forward opposition to law that is designed to protect the supply of bodies and body materials for purposes that are perceived as important. And finally it could also be that semantic distortions in legal discourse are having an effect. For example, calling dead people "donors" when in many cases all they have "done" is "failed" to object to donation whilst alive encourages a perception that there is no interference occurring in the first place.

Careful analysis exposes the fact that there clearly is an interference. The living are protected from intentional and direct invasions of their bodily security by trespass laws and the like which are actionable *per se*. In other words, the fact of the invasion itself is, irrespective of the consequences physically, treated as a legal wrong. There is no convincing reason why this should not be the same when it comes to the rights of the living in relation to what happens to their body after death. Disposition after death should even be consistent with the wishes of the incompetent person. Society normally restricts the extent to which it protects an incompetent person's wishes by reference to the need to protect other interests. In the medical context these other interests are principally clinical in nature. However, the most important interest with reference to what happens to oneself after death is clearly one's interest in having one's wishes respected. Nonetheless, in the absence of having expressed a wish one should not have one's body intruded upon.

REFERENCES

Calabresi, G. (1991) Do we own our own bodies, *Health* Matrix 1(5), 5–18.

Carvais R., Hermitte M.A. (2000) Les francais, attachés au droit commun, réticents à l'égard du droit de la bioéthique, in Carvais R, Sasportes M. (dirs.), La greffe humaine. *(In)certitudes ethiques: du don de soi a la \tolerance de l'autre*. Paris, PUF, 843–870, Circulaire Jeanneney du 24 avril 1968, 845.

Cohen, C. (1992) The case for presumed consent to transplant human organs after death, *Transplantation Proceedings* 24, 2168.

Dworkin, G. (1978) Legality of consent to non-therapeutic medical research on infants and young Children, *Archives of Disease in Childhood* 53, 443.

Feldbrugge, F.J.M. (1966) Good and bad samaritans: A comparative survey of criminal law provisions concerning failure to rescue, *American Journal of Comparative Law.* 14, 630.

Garwood-Gowers, A. (1999) *Living donor organ transplantation: Key legal and ethical Issues*, Ashgate.

Garwood-Gowers, A. (2001) Removal and use of body materials for transplantation

and research purposes: The impact of the Human Rights Act 1998, in Garwood-Gowers, A, Tingle, J, Lewis, T. (eds.), *Healthcare Law: The Impact of the Human Rights Act 1998*, Cavendish, chapter 18.

Garwood-Gowers, A. (2005) The proper limits for medical intervention that harms the therapeutic interests of incompetents, in Garwood-Gowers, A, Wheat K and Tingle, J. (eds.), *Contemporary issues in healthcare law and ethics*, Elsevier, 191–212.

Gillon, R. (1995) On giving preference to prior volunteers when allocating organs for Transplantation, *Journal of Medical Ethics* 21, 195–196.

Gunn, M., Wong, J., Clare, I.C.H., Holland, A. (2000) Medical research on incompetent adults, *Journal of Mental Health Law* February, 60–72.

Harris, J. (1975) The survival lottery, *Philosophy* 81–87.

Harris, J. (1977) The ethics of clinical research with cognitively impaired subjects, *Ital. J. Neurol. Sci Suppl* 5, 9–13.

House of Lords, House of Commons Joint Committee on the Draft Mental Incapacity Bill, Session 2002–3 (Vol 1) HL Paper 189–1, HC 1083–1 (HMSO, 28 Nov 2003).

Huffman, F.E. (1979) Coerced donation of body tissues: Can we live with McFall v Shimp? *Ohio State Law Journal* 40, 409–440.

Illich, I. (1977) *Limits to medicine: Medical nemesis and the expropriation of health*, Penguin.

Jarvis, R. (1995) Join the club: a modest proposal to increase availability of donor organs, *Journal of Medical Ethics* 21, 199–204.

Katz, J. (1972) *Experimentation with human beings*, Russell Sage Foundation, Bognor Regis.

Laslett, P. (ed.). (1960) *John Locke's Two treatises of Government,* Cambridge University Press.

Law Commission. (1995) *Mental incapacity*, Law Com, 231.

Leighday Solicitors. (2004) Nerve agent inquest finds unlawful killing, 18 November, *www.leighday.co.uk/doc.asp?doc=533&cat=923.*

Leighday Solicitors. (2005) Firms join forces to represent Porton Down veterans, 7 June, *www.leighday.co.uk/doc.asp?cat=845&doc=634.*

Maslow, A. (1976) *The farther reaches of human nature*, Penguin.

Matthews, P. (1995) The man of property, *Medical Law Review 3*, 251.

Medical Research Council. (1991) *The ethical conduct of research on the mentally incapacitated*, Medical Research Council.

Nowenstein, G. (2005) Nemo censetur ignorare legem? Presumed consent to organ donation in France, from Parliament to hospitals, in Garwood-Gowers, A, Wheat, K, Tingle, J. (eds.), *Contemporary issues in healthcare law and ethics*, Elsevier, Edinburgh, 173–188.

Pennings, G. (1995) in Englert, Y. (ed.), *Organ and tissue transplantation in the European Union: Management of difficulties and health risks linked to donors*, Martinus Nijhoff, chapter 22.

Price, D.P.T. (2000) *Legal and ethical aspects of organ transplantation*, Cambridge University Press.

Price, D.P.T. (2003) From Cosmos and Damian to Van Velzen: The human tissue saga continues, *Medical Law Review* 11(1), 1–47.

Price, D.P.T. (2005) The Human Tissue Act 2004, *Modern Law Review* 68(5), 798–821.

Rodgers, M.E. (2003) Human bodies, inhuman uses: Public reactions and legislative responses to the scandals of bodysnatching, *Nottingham Law Journal* 12(2), 1–17.

Rogers, C. (1978) *On personal power*. New York: Dell.

Rothman, D. (1997) Bodily integrity and the socially disadvantaged: The traffic in organs for transplantation, in Spielman, B. (ed.), *Organ and Tissue Donation: Ethical, Legal and Policy Issues*, Southern Illinois University Press, Carbondale, 35.

Singer, P. (1972) Famine, affluence and morality, *Philosophy and Public Affairs* 1, 229.

Skegg, P.D.G. (1988) *Law, ethics and medicine*, Clarendon Press, Oxford.

Thomson, J.J. (1971) A Defense of Abortion, *Philosophy and Public Affairs* 1, 48.

Tomossy, G.F., Weisstub, D.N. (1997) The reform of adult guardianship laws: the case of non-therapeutic experimentation, *International Journal of Law and Psychiatry* 20, 113.

Veatch, R. (1995) Consent for perfusion and other dilemmas with organ procurement from non-heart beating cadavers, in Arnold, R, Youngner, S, Schapiro, R, Mason-Spicer, C. (eds.), *Procuring organs for transplant: The debate over non-heart beating cadaver protocols*, John Hopkins University Press, Baltimore, 195.

Zilgalvis, P. (2004) European law and biomedical research, in Council of Europe (ed.), *Biomedical Research*, Council of Europe.

INDEX

Adult guardianship, 155, 159, 162, 164
Advocacy, 67, 298, 326
Amnesty International, 13
Antenatal diagnosis, 219, 221
Attributed dignity, 27
Autonomy
  "life-time" autonomy, 116–119
  patient autonomy, 83, 111, 189, 190, 198, 200
  pediatric autonomy, 119–120
  "present-day" autonomy, 116, 119
Autonomy rights, 159, 160

Bioethics, 1–2, 4, 11–21, 75–86
Biolaw, 2, 75–86
Biomedicine, 5–6, 19, 25, 81, 175, 249, 283, 346
Bodily security
  incompetent persons, 378, 387, 391, 393, 395
  legal protection, 375–387
  legal reform, 160, 309, 310, 311, 318

Canada
  community treatment orders, 320
  health Care Consent Act, 1996, 319
Canadian Charter of Rights and Freedoms, 309, 312, 313
Civil rights, 46, 69, 155, 156, 166, 302, 316
Civil society, 46, 50, 53, 157, 158, 161, 166
Clinical justice, 258
Clinical trials, 301, 333, 336, 346
Cloning
  Declaration of Helsinki, 278, 342, 376, 383
  eugenics, 272, 281
  human, 271–286
  human cloning and the law, 283
  reproductive cloning, 282
  right to freedom of research, 277
  therapeutic cloning, 272, 273, 282
  Universal Declaration on the Genome and Human Rights, UNESCO, 278
Co-responsibility, 42
Commodification, 11, 12
Communitarianism, 19, 157, 164–166
Compulsory genetic testing, 219, 223
Constitutive rules, 192, 196, 198
Contractualism, 161–166
Convention for the Elimination of Discrimination Against Women CEDAW, 58
Council of Europe, 217, 218, 219, 220, 283, 376
Cultural rights, 56, 60, 68, 291

Death
  brain death, 236–238, 244, 245, 247, 250, 251
  brain death in Japan, 3, 356
Decisional capacity, 111
Domestic violence
  battered-woman syndrome, 130
  child abuse, 131, 132, 133, 135
  children and adolescents, 131
  domestic violence, 131
  parricide, 135
  sexual abuse, 126, 127, 128, 130, 131, 133, 134, 135, 136, 137
  statistical studies, 125
  typology, 127
  uxoricide, 125
Domestic violence, 125
  psychiatric illness, 136

Eugenic practices, 227
Europe, 57, 205
European Convention on Human Rights and Biomedicine, 25, 218, 222
European Council, 221, 272, 281
Euthanasia
  decriminalization, 205
Experimental treatment, 345, 356, 359

Female circumcision
  FC/FGM, 57, 66
Female genital mutilation, 55, 66
Foundationalist challenge, 55, 61, 62
Freedom from torture, 155
Freedom of choice, 38, 41, 191, 198, 199, 355

GECIEB
  The European Advisory Group on the Ethical Implications of Biotechnology, 280
Genetic counselling
  confidentiality, 220, 221, 222, 229
  pre-conception diagnosis, 222
  pre-implantation diagnosis, 223
  pre-natal diagnosis, 224
Genetic screening, 217–220, 223, 226, 227

Health care
  communitarian rights, 292
  distribution, 303
  rationing, 295, 299
Hierarchy of rights, 60, 62, 64, 65, 66, 67, 68
HIV/AIDS
  AIDS research, 334
Human dignity, 25–29
Human experimentation, 284, 345, 346
Human genome, 91, 218, 219, 224, 271, 275, 278, 281
Human rights
  negative rights, 26, 33, 68
  positive rights, 26, 155, 156, 167, 309, 316, 320

International Bill of Human Rights, 56, 57
International Covenant on Civil and Political Rights, 56, 227, 311
International Covenant on Economic, Social and Cultural Rights, 56, 311
Intrinsic dignity, 27
Intrinsic value, 28, 29, 30, 32, 33, 76, 281
Involuntary treatment, 158, 318

Japan
  mentally ill populations 149
  terminally ill population 148, 149
Japanese humanism, 146

Male privilege, 60
Medical ethics, 5, 19, 20, 21, 32, 82, 83, 144, 146, 189, 190, 198, 199
Mental health rights
  anti-rights, 323
  historical legacy, 310
  MI Principles, 312, 320, 321, 325, 326
  Ontario Consent and Capacity Board, 319
Mental health tribunals, 160
Minors
  adolescents, 131
  decisional authority, 111, 112, 115, 116, 119
  decisional capacity, 111
  parens patriae doctrine, 314
  unemancipated adolescents, 115
Minors' rights
  Legal & professional considerations, 112
Moral agent, 39, 40, 82, 93
Moral rights, 45
  multiculturalism, 175, 182, 205

Natural Law, 46
Natural rights, 26, 33
Naturalism, 178
Nuremberg Declaration, 82

Organ donation
  cadaveric organ donation, 243
  cadaveric organs, 235, 242, 244
  consent, 242, 245–246
  cross-cultural attitudes, 236
  cultural meaning systems, 240
  organ donor rates, 246
  presumed consent, 245–246
  sociocultural beliefs, 238
  surrogate decision makers, 239
  transplant policies, 240, 242, 262, 264
  transplant policy goals, 262

Paternalism, 82, 83, 144, 157, 158, 209, 338, 378
Patient-physician relationship, 191, 192, 193, 201, 305
Patient vulnerability, 85
Patients' rights, 85, 190, 198, 200
Pediatric decisions
  third party interests, 120
Pediatric research, 342, 344
Personalism, 89, 90
Personhood, 29
Personism, 90
Pluralism, 1–2, 37, 83, 89, 173, 189
Positive legal rights, 47
Postmodern, 15, 16, 89, 155
Postmodernism, 161

Reproductive health rights, 58
Research ethics
  accountability, 335
  pharmaceutical trials, 340
  short course AZT Trials, 331
  vulnerable subjects, 337
Research imperative, 342–345
Research protocols, 341, 353, 366
Retributive justice, 63, 198
Right to die, 52
Right to health care, 53
Right to life, 52
Romanticism, 174

Secularization, 83
Social contract, 2, 12, 38, 45, 52, 77, 344
Social security
  social security, 101, 102, 103, 107, 108
Spain
  Constitution, 101, 104, 105, 106, 108, 206, 210, 212, 278
  Constitutional Court, 105, 106, 107, 210, 212
  organ donation rate, 4, 235, 243, 245, 246, 247, 248
Stipulative definition, 31, 32
Stipulative rights, 26
Suicide
  ethics and legal considerations, 356
  experimental methodologies, 359
  libertarian perspective, 355
  moralist perspective, 208
  relativist approaches, 355
  research ethics, 329–349
  suicide research, 353–371
  vulnerability, 75, 77, 80–86

Torture, 13, 52–53, 62
Tuskegee experiments, 331

UNESCO, 217, 218, 219, 220, 275, 276, 278, 279, 284
United Nations Charter, 56, 57
Universal Declaration of Human Rights, 25, 45, 46, 56, 61, 227, 291
Universal human rights, 26
UNOS, 257, 259, 263, 264, 265

Vulnerable populations, 148

Welfare rights, 99–107
Welfare State 3, 4, 77, 99, 100, 101, 104, 105, 106, 107, 163, 166, 167
Women's rights, 18, 58, 59, 60, 61, 62, 63, 64, 65, 68
World Health Organization, 14, 56, 217, 291, 353, 358

International Library of Ethics, Law, and the New Medicine

1. L. Nordenfelt: *Action, Ability and Health*. Essays in the Philosophy of Action and Welfare. 2000 ISBN 0–7923–6206–3
2. J. Bergsma and D.C. Thomasma: *Autonomy and Clinical Medicine*. Renewing the Health Professional Relation with the Patient. 2000 ISBN 0–7923–6207–1
3. S. Rinken: *The AIDS Crisis and the Modern Self*. Biographical Self-Construction in the Awareness of Finitude. 2000 ISBN 0–7923–6371–X
4. M. Verweij: *Preventive Medicine Between Obligation and Aspiration*. 2000 ISBN 0–7923–6691–3
5. F. Svenaeus. *The Hermeneutics of Medicine and the Phenomenology of Health*. Steps Towards a Philosophy of Medical Practice. 2001 ISBN 0–7923–6757–X
6. D.M. Vukadinovich and S.L. Krinsky: *Ethics and Law in Modern Medicine*. Hypothetical Case Studies. 2001 ISBN 1–4020–0088–X
7. D.C. Thomasma, D.N. Weisstub and C. Hervé (eds.): *Personhood and Health Care*. 2001 ISBN 1–4020–0098–7
8. H. ten Have and B. Gordijn (eds.): *Bioethics in a European Perspective*. 2001 ISBN 1–4020–0126–6
9. P.-A. Tengland: *Mental Health*. A Philosophical Analysis. 2001 ISBN 1–4020–0179–7
10. D.N. Weisstub, D.C. Thomasma, S. Gauthier and G.F. Tomossy (eds.): *Aging: Culture, Health, and Social Change*. 2001 ISBN 1–4020–0180–0
11. D.N. Weisstub, D.C. Thomasma, S. Gauthier and G.F. Tomossy (eds.) *Aging: Caring for our Elders*. 2001 ISBN 1–4020–0181–9
12. D.N. Weisstub, D.C. Thomasma, S. Gauthier and G.F. Tomossy (eds.): *Aging: Decisions at the End of Life*. 2001 ISBN 1–4020–0182–7
    (Set ISBN for vols. 10–12: 1–4020–0183–5)
13. M.J. Commers: *Determinants of Health: Theory, Understanding, Portrayal, Policy*. 2002 ISBN 1–4020–0809–0
14. I.N. Olver: *Is Death Ever Preferable to Life?* 2002 ISBN 1–4020–1029–X
15. C. Kopp: *The New Era of AIDS*. HIV and Medicine in Times of Transition. 2003 ISBN 1–4020–1048–6
16. R.L. Sturman: *Six Lives in Jerusalem*. End-of-Life Decisions in Jerusalem-Cultural, Medical, Ethical and Legal Considerations. 2003 ISBN 1–4020–1725–1
17. D.C. Wertz and J.C. Fletcher: *Genetics and Ethics in Global Perspective*. 2004 ISBN 1–4020–1768–5
18. J.B.R. Gaie: *The Ethics of Medical Involvement in Capital Punishment*. A Philosophical Discussion. 2004 ISBN 1–4020–1764–2
19. M. Boylan (ed.): *Public Health Policy and Ethics*. 2004 ISBN 1–4020–1762–6; Pb 1–4020–1763–4
20. R. Cohen-Almagor: *Euthanasia in the Netherlands*. The Policy and Practice of Mercy Killing. 2004 ISBN 1–4020–2250–6
21. D.C. Thomasma and D.N. Weisstub (eds.): *The Variables of Moral Capacity*. 2004 ISBN 1–4020–2551–3
22. D.R. Waring: *Medical Benefit and the Human Lottery*. An Egalitarian Approach. 2004 ISBN 1–4020–2970–5

International Library of Ethics, Law, and the New Medicine

23. P. McCullagh: *Conscious in a Vegetative State? A Critique of the PVS Concept*. 2004 ISBN 1–4020–2629–3
24. L. Romanucci-Ross and L.R. Tancredi: *When Law and Medicine Meet: A Cultural View*. 2004 ISBN 1–4020–2756–7
25. G.P. Smith II: *The Christian Religion and Biotechnology*. A Search for Principled Decision-making. 2005 ISBN 1–4020–3146–7
26. C. Viafora (ed.): *Clinical Bioethics*. A Search for the Foundations. 2005 ISBN 1–4020–3592–6
27. B. Bennett and G.F. Tomossy: *Globalization and Health*. Challenges for health law and bioethics. 2005 ISBN 1–4020–4195–0
28. C. Rehmann-Sutter, M. Düwell and D. Mieth (eds.): *Bioethics in Cultural Contexts*. Reflections on Methods and Finitude. 2006 ISBN 1–4020–4240–X
29. S.E. Sytsma, Ph.D.: *Ethics and Intersex*. 2006 ISBN 1–4020–4313–9
30. M. Betta (ed.): *The Moral, Social, and Commercial Imperatives of Genetic Testing and Screening*. The Australian Case. 2006 ISBN 1–4020–4618–9
31. D. Atighetchi: *Islamic Bioethics: Problems and Perspectives*. 2006 ISBN 1–4020–4961–7
32. V. Rispler-Chaim: *Disability in Islamic Law*. 2006 ISBN 1–4020–5052–6
33. Y. Denier: *Efficiency, Justice and Care*. Philosophical Reflections on Scarcity in Health Care. 2007 ISBN 978–1–4020–5213–2
34. Y. Hashiloni-Dolev: *A Life (Un)Worthy of Living*. Reproductive Genetics in Israel and Germany. 2007 ISBN 978–1–4020–5217–0
35. M.A. Roberts and D.T. Wasserman (eds.): *Harming Future Persons*. Ethics, Genetics and the Non-identity Problem. 2008 ISBN: 978-1-4020-5696-3
36. D.N. Weisstub and G.D. Pintos (eds.): *Autonomy and Human Rights in Health Care*. An International Perspective. 2008 ISBN 978-1-4020-5840-0