Arima Mishra · Kalyani Subbiah *Editors*

Ethics in Public Health Practice in India

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Foreword

Now we feel ethics is everywhere (Comment from a student reported in Chapter 10)

This book's creation comes from a meeting that was held at Azim Premji University, Bangalore, in 2014 to address public health education where 'the need for conscious nurturing of ethical values of public health' was stated and the concept of 'public health ethics as an enquiry' debated. The words enquiry, values and conscious are the key in the role of education in public health ethics in the twenty-first century. How do we help students to be inquisitive about public health and to enquire into difficult ethical dilemmas? How do we work to instil values and what should they be, and how do we help raise their consciousness of the issues and importance of public health ethics as a subject?

In the first chapter, it says that 'public health ethics as a field of enquiry is at a nascent stage in India' with its knowledge and wisdom slowly emerging and yet, in terms of ancient philosophical wisdom as well as important case studies that highlight local, national and international issues around public health ethics, India already has much to teach each of us about life and death, about health and disease, about community and population and about how each of these issues relates to public health and to ethics. The scale of the Indian situation in terms of land and population brings to the fore the major international issues of the day in ethics, and each of the chosen authors provides an important unique perspective on public health ethics in India with chapters focussing on teaching, rights, programme design and evaluation, analysis of public health programmes, the role of public health ethics in the design of non-public health programmes, data ethics, ethics issues in gender and reproductive technologies, qualitative research on health systems, teaching ethics in medical college and finally a description and analysis of the course in public health ethics at the Azim Premji University.

Important themes emerge from these chapters: education and the human condition, self-reflection and relationship; community, values and education; and the individual versus the population which is at the heart of public health ethics and how to balance the needs of the individual versus the needs of the population. The powerful theme of education dominates the book and provides insights into how to enquire about ethical values, how to nurture them and how to work with them in public health situations.

Themes that Emerge in the Book

The Individual Self

The individual self is highlighted in the book. Who am I and what role am I playing in public health? Am I an educator, a student, a medical officer or a data analyst, and what values do I bring to my work in public health? Each of the authors provides a different perspective.

Ethics is about actions, and therefore, in a sense, everything we do is about ethics as is noted in the quote to this foreword from a student at Azim Premji ‘now we think ethics is everywhere’. Another student said ‘ethics is humane and it is important that one looks within first before trying to address any others issues out there’. It is essential therefore that each of us does just that. The better each of us understands ourselves, who we are and our roles in public health, the better for the communities and populations that we serve.

However, as ethics constantly reminds us, knowing ourselves and being better able to empathize and relate to others only happens through constant self-reflection and debate. The individual self-reflection that is highlighted in Chaps. 1, 6 and 10 is paramount and an important discipline for each of us in our public health work. Self-reflection is part of qualitative research methods, and qualitative researchers understand this with Chap. 6 on qualitative research in health systems highlighting this point. However, it should also be an important discipline in epidemiology and in those of us who work with quantitative data sets where there is a need to ponder and reflect on all those individuals that are present in our population datasets and to try and understand how our actions (our ethics) will affect each one of them. It is a hard task, but I would say that for public health practitioners, this is an essential task and one that is never completed.

Relationship

Of course relationship is important in public health because our roles and actions have the potential to affect a large number of individuals. So, our ability to understand and to relate to others and to become more sensitive and to be better able to empathize with the issues, experiences and outcomes of people in different contexts is important. The importance of vulnerability in life and vulnerability in public health is highlighted (Chaps. 2, 5, and 8). How are people who sit at the edge, on the margins of our societies, treated? What are their rights, and what are the ethics and actions that are taken by practitioners to ensure that their vulnerability is respected and treated accordingly?

Communities

As we relate to others so we can then better relate to communities. Participation of communities in all the stages of research is essential (Chap. 3) as is the need for process and dialogues that is needed to find the best way forward in public health decision-making (Chap. 4). This is challenging but essential as ‘The population or community perspectives of public health is critical’ (Chap. 1) with the importance of local decision-making in designing programmes to find the appropriate action coming to the fore in the environmental ethics issues surrounding the endosulfan tragedy (Chap. 5).

Values

What are the values that support our work? The importance of the high ideals and principles of medical ethics is noted in the intention of St. John’s Medical College in Bangalore ‘to instil the principles of moral values into the student so that they could maintain high professional standards and integrity of life’ (Chap. 9). The ancient wisdom of India present in the ancient codes of ethics and values that are presented in classical Ayurveda is also mentioned in this chapter. Ayurveda is about the ‘knowledge of life’, and its wisdom is profound and its knowledge and education need to be brought forward into current medical and public health ethics. Ayurveda understands what health is, unlike our Western systems that are about disease and not about health.

Education

How public health ethics is taught is a challenge. The course at Azim Premji has clearly been very successful, and Chap. 10 explains the constituents of the course and its success. There are some wonderful insights from the students: ‘This course has been a personal journey for me where I have constantly thought within myself to understand the confusion that emerged……’; ‘I had never thought that one needs to ask so many questions in the understanding of what happens and why it happens’.

The course is clearly challenging and asks difficult questions like ‘What are we training public health professionals for? Is it for the market or to be able to respond to national needs?’ With the increasing medicalization of life happening around the globe, we need to increasingly ask basic questions around education and training and to ensure that the values inherent in public health practice through its service to communities are honoured. Public health is not about the market or about profit, it is about life, individuals, communities and well -being.

Wisdom and Values that Are Important to Public Health Ethics

I agree with the student who says that ‘ethics is everywhere.’ The thinking and feeling self that is described in so many different places in this book provides us with the knowledge of life that includes important insights into ethics, roles and values. How do I relate to myself and to others, and what values are important in my relationships with individuals and with communities? The ancient Indian local health traditions provide enormous insight into the self, to health (‘swastya’, bring rooted within) and highlight the importance of values in individuals, in communities and in societies. These are the values that relate to the outside world through relationship (Yamas, non-violence, truth, non-stealing, celibacy/marital fidelity and non-possessiveness) and to the internal values that each of us holds within ourselves (Niyamas, purity of body and mind, contentment, self-discipline, self-reflection and true self). These values are essential, as are the roles of feeling, of empathy and of compassion in making us human. The teachings also indicate that before any action is taken, each of us needs to reflect on all these parts of ourselves. So, ‘everything is ethics’!

Conclusion

I have been waiting for a book like this and delighted to be able to write a Foreword. India has such a wealth of knowledge in ethics and public health, and the rest of the world needs more Indian writing on public health ethics, more writing that brings forward the ancient knowledge of the country and the ancient wisdom and teachings that percolate through life and the Indian system. This book is a wonderful start to this process to ensure that public health ethics is no longer ‘nascent’ in India, and I believe that the publication of this book suggests that India has begun to take a powerful role in bringing the importance of public health ethics into the foreground of health and health care, and I hope this book is simply the start of more publications on ethics from Indian researchers and public health practitioners.

John D. H. Porter

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July 2018

Preface

Public health, by its very definition, concerns and engages with the health and well-being of a population and focuses on the curative, preventive, promotive and rehabilitative aspects of that population's health. These aspects rely on the allied values and goals of equity, social justice and human rights. While it is acknowledged that ethics is at the core of achieving the goals of public health, ethical analysis is mostly assumed than consciously nurtured and applied in public health practice. This edited volume on 'Ethics in Public Health Practice in India' has been conceived to locate ethics at the centre stage of public health practice. In the process, it seeks to explicate ethical analysis of public health issues, deliberations and resolutions.

The idea of this volume germinated in a visioning meeting on public health education in India organized by us at the Azim Premji University in 2014. The meeting was sought to be the first in a series of such consultations in order to identify the niche for Azim Premji University to contribute to public health education, research and training in India. More than 40 participants representing 20 institutions (universities, civil society organizations and research institutes) having long-standing engagement with public health/community health participated in this deliberation. The meeting provided a reflective forum for reinstating the community/population orientation of public health, the concerns for increasing medicalization, technologization of health, high out-of-pocket expenditure in meeting health needs and persistent health inequities. It was strongly felt that public health has a 'social' purpose (unlike medicine that speaks to individual forms of care) that puts the 'public' (attentive to the needs of marginalized communities) and 'health' (all components of health) at the centre stage. Hence all components of public health practice (policy, program planning/implementation, research, monitoring and evaluation, training) must contribute to this purpose. This discussion hence established the need for conscious nurturing of ethical values of public health. This visioning meeting was followed by several formal and informal consultations with public health professionals in taking some of the discussions forward. These discussions brought out the need for explicit deliberations of public health ethics and the limitations of current frameworks of clinical and bioethics to adequately capture public health issues and concerns. In the same vein, internationally available ethical guidelines and protocols remain fraught with the difficulties of context-specific applicability in settings that have social, religious and legal realities that are unique and distinct from one another in a country setting like India. This volume grew out of this collective concern and felt need for unpacking public health ethics as a distinctive field of inquiry. As part of this effort, we launched (2016–2017) a short 1-week training program on Ethics in Public Health Practice for in-service public health professionals. Most of the contributions to this volume came from the sessions facilitated by public health scholars during this training program. Additionally, we reached out to others whose work significantly sought to contribute to shape this evolving field of inquiry.

The volume draws on ten original contributions from academics and practitioners in varying roles and long-standing engagement with public health in diverse settings within India. The contributors are drawn from different disciplines and areas of work including anthropology, sociology, health communications, gender studies, economics, epidemiology, social work and medicine with a shared commitment to the community orientation and societal understanding of public health that locates health necessarily in its social/cultural/political determinants. Their perspectives and experience, as a result, span a gamut of ethical enquiries including ethics and rights; complex health systems; design, implementation and evaluation of public health (and non-health) programs; research and advocacy on gender and new reproductive technologies; managing datasets in the information age; capacity-building; and teaching of public health ethics in medical schools and universities. Public health has evolved as a discipline with much stronger and robust engagement with contributions from social sciences, and this volume reflects this interdisciplinary orientation of public health.

The volume runs through four parts. Part I provides an introduction to the field of public health ethics and analysis and moves on to present the juxtaposition of rights and ethics and specific forms of contestations in the legal, social and health systems contexts in India. This part seeks to throw light on the key manifestations and influences of history in public health ethics in one platform. It also intends to set the foundation to better understand the echoes and dissents of this history today. Part II emphasizes the complex nature of programs in public health through cases that illustrate both their possibilities and pitfalls in design, enquiry and analysis, stakeholder management, adverse events, monitoring and evaluation. This part's unique contribution is to introduce ethics into design, implementation and evaluation of public health programs. Despite the fact that programs have been the predominant modes through which policies are operationalized, ethical lens in the analysis of public health programs is assumed or absent. Programmatic challenges and disconnects are diagnosed, at best, as implementation failures and not as ethical/moral failures.

Part III discusses ethical issues in different kinds of public health research settings and themes. These include the risks and benefits of large datasets in a constantly changing information age and the need for vigilance in the management of data pools with confidential and private health information. The part also includes reflections on doing qualitative research in/on health systems and its complexities and the ethical tensions at the crossroads of different epistemological traditions and specific interpretations of ethical tenets including individual autonomy and privacy. Experiences on research and advocacy on reproductive technology and commercial surrogacy and its myriad ethical aspects from a feminist lens are further discussed. This part also conveys how the boundaries between research and practice/advocacy are blurred in public health settings necessitating a revisiting of standard research ethics guidelines. Part IV discusses the criticality of human resources, upgrading curricula in forums of learning, teaching and training opportunities designed for students and young professionals who are set to enter and practise public health. Both the chapters in this part share their reflections of the opportunities and challenges of teaching public health ethics in two different institutional settings and programs (a medical college and university setting).

Every chapter either directly or indirectly reveals that ethical dilemmas or challenges cannot be contained as a checklist in a textbook or protocol in the best of circumstances. Ethical problems rarely have one standard resolution, and it is the rigor in the processes, deliberations and reflections that responses are likely to emerge. The contributors also suggest that these resolutions need to be concurrent with the facts, values and contexts in which they occur. Further, the volume tries to go beyond understanding ethics from its application in health-care service delivery and/or research settings, which traditionally garner the maximum attention, interest and focus in such literature. The four parts together expand the ethical lens to different aspects of public health practice including teaching, research and program design/implementation/evaluation. The contributions, we hope, will be an initial step to facilitate forums for future dialogues and platforms for different other dimensions of public health ethics. The volume is not meant to be closed and complete in discussing ethics in all aspects of public health practice. There are many other critical arenas including mental health, addressing other non-communicable diseases, traditional medicine/healing, role of media, community monitoring, and community-based participatory research and many more where ethical issues need to be discussed and deliberated.

The book is conceptualized to reach broader audiences such as public health practitioners and researchers in settings ranging from the government health systems to NGOs/Grassroot organizations/CSR (Corporate Social Responsibility) initiatives/advocacy groups as well as researchers in academic settings and those involved in teaching ethics and training initiatives for students and young practitioners.

We thank and acknowledge every experience, participant, setting and contributor that has made this venture possible. Specifically, we wish to thank the participants in the visioning meeting and subsequent consultations, our colleagues and students in the university whose inputs have enriched our understanding of this field. Last but not the least, we greatly appreciate the time and efforts of the contributors who have made this volume truly a collective endeavour. We missed some colleagues who had

willing to contribute (and shared their abstracts) but could not do so due to other commitments. We nevertheless have benefitted from their work and hope to have their continued engagement in public health ethics deliberations beyond this volume. We also wish to thank our family members for supporting us in this thoughtful exercise. Thanks are due to the reviewers whose suggestions have helped in strengthening the volume.

Bangalore, India Arima Mishra
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Editors

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Kalyani Subbiah has several years of experience in public health research, communication and teaching in India. Her work is committed to risk-reduction, accessibility to preventive measures and promotion of women's health through ethical responsibility of programs, research and key functionaries in health systems. Kalyani is currently pursuing a PhD in International Health at the Faculty of Health Sciences, Curtin University, Australia, with the support of an Australian Government Research Training Program Scholarship.

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Part I

Introduction to Public Health Ethics and Rights

Chapter 1
Locating Public Health Ethics

Arima Mishra and Kalyani Subbiah

Abstract Several global health challenges including emergencies like Ebola, environmental disasters, rising epidemic of noncommunicable diseases, and persisting health inequities, among others, have raised serious concerns about public health goals and practices and necessitate an ethical lens to the "lessons learned" from such challenges. The last two decades or so have witnessed an increasingly explicit engagement with public health ethics in academic and professional forums trying to carve out a distinct field of inquiry – distinct from clinical and bioethics though sharing a historical legacy with these two fields. This chapter joins this conversation to map this emerging field of inquiry in the context of public health goals and values, and examine its implications in the context of India. The chapter shows how ethics is at the heart of public health practice and the methodology of doing public health ethics demands a critical and reflective lens that discerns ethical dilemmas/challenges in everyday practice and resolved through individual and collective deliberations. Ethics in public health practice is hence not a one-off activity of seeking ethical approval for research. It involves application of an ethical reasoning in all components of practice including policy making, program design/implementation/monitoring/evaluation, different kinds of research, and communication and advocacy.

Public Health Ethics as a Distinct Field of Inquiry

In their provocatively titled article "Ebola and Learning Lessons from Moral Failures: Who Cares about Ethics?, Smith and Upshur (2015:305) remind the global health community that "We cannot continue to fiddle at the margins without critically reflecting on our repeated moral failings and committing ourselves to a set of

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values that engenders an approach to global public health emergencies that embodies a sense of solidarity and global justice." Several global health challenges including emergencies like Ebola, SARS, environmental disasters, health risks of climate change, rising epidemic of noncommunicable diseases, and persisting health inequities, among others, have raised serious concerns about public health goals and practices and necessitate an ethical lens to the "lessons learned" from such challenges (Smith and Upshur 2015; Verweij and Dawson 2018). Ethics is not new to public health. Ethical challenges expressed in terms of the role of the government vis-à-vis individuals/populations have been discussed and debated throughout the history of public health. However, the nature of ethical issues has expanded as public health itself has evolved as a discipline and extended its ambit of interventions in response to continuing and emerging health conditions (Beauchamp and Steinbock 1999; Kass 2001). The last two decades or so have witnessed an increasingly explicit engagement with public health ethics in academic and professional forums trying to carve out a distinct field of inquiry – distinct from medical and bioethics though sharing a historical legacy with these two fields. The increasing number of books (Beauchamp and Steinbock 1999; Anand et al. 2004; Dawson 2011; Holland 2015; Peckham and Hann 2010; Barret et al. 2016 to name a few) and discussions in journal forums including the launch of an exclusive journal on *Public Health Ethics* in 2010 are indicative of this evolving field of inquiry.

The distinctiveness of public health ethics rests on the goals and values of public health itself. Public health, unlike clinical medicine, commits itself to protecting and promoting the health of the *population*. Public health hence uses "socially oriented strategies rather than individually oriented actions to achieve this goal" (Kass 2004:232). The population or community perspective of public health is critical. Beauchamp and Steinbock (1999) emphasizes the communitarian language of public health to imply that we, as a community, have a shared commitment to one another and to promote health as a common/public good through collective actions. Such collective orientation of public health underlines its distinctive "orientation towards groups and communities as something over and above a collection of individuals" (Cribb 2010:22). The Institute of Medicine's definition of public health in 1988 explicates and reinforces the community orientation of public health as "Public health is, what we as a society, do collectively to assure the conditions in which people can be healthy" (Institute of Medicine 1988:1). These discussions unravel in many ways the question of who/what constitutes the "public" in public health and its ethical implications. While Beauchamp (1983) in his essay on "what is public about public health" reinforces the communal and shared orientation of the notion of public, others disentangle to highlight the aspects of numeric public (target population), political public (the government and public agencies with a political mandate of shouldering collective responsibility), and the communal public (that includes all forms of social and collective action by a range of actors) (Childress et al. 2002). The notion of public/population gets further complicated when one is confronted with extensive evidence on health inequalities. The inherent challenge in unpacking the notion of the "public" is the heterogeneous nature of societies with different social locations of individuals having distinct privileges and priorities. The ethical challenges begin with when such inequalities (based on race, gender, ethnicity, class, or any other) or societal arrangements are considered as natural and given. The WHO Commission on Social Determinants of Health report (2010) succinctly states that it is not diseases but social injustice that kill people on a grand scale. Hence it is not inequality per se but how policies, politics, and social/cultural arrangements act on unequal social positions of individuals that do matter in reducing health inequities in a society (Mishra 2018).

If the communitarian language of public health rests on fundamental values of solidarity and social justice, the evidence on persistent health inequalities mandates that the understanding of the population/public and the causes of inequalities must be more nuanced taking into account the structural determinants of health. The communitarian language also brings to the fore the question of agency and responsibility in public health ethics – "it is always relevant to ask who has responsibility for what?" (Cribb 2010:20). Considering the fact that public health as a collective enterprise needs to draw on multiple stakeholders involving the government, community, NGOs, corporate social responsibility, private companies (the roles of some of these stakeholders has become more prominent in the recent times), the ethical question of shared responsibility is much more complex in public health than in a clinical setting that has the practitioners and patients as the center of interactions.

Apart from the population/community orientation of public health, the mandate of public health to address the causes of ill-health, disability, and injury thus addressing the structural and social determinants of health is an important point of departure from clinical medicine (Mann 1997; Gostin 2001; Anand et al. 2004; WHO 2010). The tensions between a narrow (health care, morbidity, mortality) and broad conception of health (addressing causes of ill-health to create conditions for healthy communities) thus between health and health care is age-old but continues to be relevant from the perspective of public health ethics (Gostin 2001; Cribb 2005, 2007, 2010). Though these conceptions are not mutually exclusive (health care is critical to public health), confining public health to provision of health care alone would be ethically problematic. Beginning with the Black Report of the UK in 1980 followed by many others including the recent WHO Commission on Social Determinants of Health as well as the social science literature, there has been a rich body of theoretical and empirical work to suggest that addressing social determinants of health is critical to create the conditions conducive to make people healthy. In fact the recent literature has expanded the understanding of social determinants of health itself and discusses about actions that could possibly address such determinants whether it is gender-based violence or unresponsive health systems (Mishra 2018; Nambiar and Muralidharan 2018; Navarro 2009; Samuelsen et al. 2013; Farmer et al. 2006; to name a few). The mandate of public health itself, thus, demands an inter-sectoral and multidisciplinary approach where provision of health is beyond the health sector/health system alone unlike provision of medical care in the field of medicine. From this mandate, public health ethics rests on a *societal* understanding of public health that upholds values of equity, rights, and justice and locates health necessarily in the larger social, political, and economic arrangements that promote/protect/prohibit health. Hence public health ethics may have a historical legacy in medical and bioethics but expands its scope and orientation to include understanding of communities, health systems, global health, and environmental justice (Beauchamp 1999; Kass 2004; Cribb 2010). Power is central to such understanding (Rogers 2006). This “social turn” (Cribb 2005) is a critical point of departure for delineating the field of public health ethics.

Unlike clinical medicine, public health is an eclectic and evolving field of inquiry. The interdisciplinary orientations of public health have been more systematically developed in the recent times through conceptualizing the field of health policy and systems research (HPSR). Breaking itself away from a techno-managerial approach of mainstream public health, HPSR reinstates and reinforces the societal and political understanding of policies and practices in public health (WHO Alliance 2007; Ghaffar et al. 2012). Social sciences have played a major role in shaping HPSR (Gilson 2012; Sheikh et al. 2011; Mishra 2013). Its implications for public health ethics are manifold. Social science perspectives not only thicken our understanding of actors, contexts, and processes but problematize the framing of public health issues themselves arguing that “the ways in which public health problems and solutions are constructed may reinforce certain moralizing discourses, may alter the distribution of health experience whether narrowly or broadly conceived, or may produce or reproduce patterns of discrimination or stigmatization. Critical social science provides powerful tools to help expose and illuminate these dangers and for this reason, enriches ethical reasoning” (Cribb 2010:28). Such perspectives thus extend the ethical inquiry to include not only to ask if public health interventions are fairly distributed but why *this* particular intervention and processes of production, consideration of evidence, and decision-making. Chapter 3 in this volume addresses this question of framing of program design and evaluation in the context of plurality of knowledge and evidence. HPSR thus extends and expands ethical issues and modes of approaching them beyond the conventional ethics of clinical medicine or even research ethics establishing the need for appropriate guidelines for HPSR work (Luyckx et al. 2017; Pratt et al. 2017; Gopichandran et al. 2016). As Luyckx et al. (2017) argue, HPSR sets its work in “real-world” contexts, contrasted with a clinic setting addressing single disease entity, and hence cannot have research protocols that are only about individual autonomy, consent, and balancing risks and benefits rather need to consider protecting participants from exploitation, responsibility, and accountability of researcher in building local research capacity, preventing risks of exacerbating inequality during the course of research, addressing ancillary needs, etc. Hence guidelines for review of research under HPSR cannot follow conventional guidelines for biomedical research. Some of these tensions in the ethics committees’ reviews of HPSR as well other issues are discussed in Chap. 6 in this volume.

This does not mean that the seminal ethical guidelines in health research and care are insignificant to the discussion of public health ethics. The last 75 years have been foundational in laying the road for the ethical accountability and responsibility we share collectively as the human race toward better health and well-being. However, locating public health issues and ethics better has also been pivotal in helping us evaluate whether established codes require revisiting in the changed annals of time, culture, vulnerability, and participatory representation specifically in the context of the mandate and goals of public health practice. The Nuremberg Code in 1947 and the 1964 Declaration of Helsinki (Porter and Venkatapuram 2012) commenced the key requirement of collective responsibility through two crucial dimensions: (a) highlighting the accountability of medicine, research, experimentation, rights, information, and consent in health and (b) acknowledging the need for clear guidelines in health-care provision and service. This journey in turn facilitated the inclusion of other crucial milestones in ethical principles, including the principles approach that gave increasing credence to autonomy, beneficence, non-maleficence, and justice to all people in a health system. The birth of "bioethics" in the 1960s and 1970s has important lessons for public health ethics. Its contributions to the areas of ethics of health promotion, resource allocation, and the societal rights vs individual liberties to justice and access to care specifically emanating from HIV/AIDS policies and interventions have continued to be relevant for public health discussions. Bioethics' inroads into the ethical issues at stake in the use of different kinds of medical/biotechnology, organ donations, and other invasive medical practices have been critical (Schicktanz et al. 2010; Kass 2004). While bioethics continues to remain critical in guiding ethical processes of biomedical research, public health scholars have identified the limitations of its applications to public health research and practice. The last two decades or so have witnessed the emergence of emphasis on more comprehensive health-care reforms, sharper engagement with health inequality, focus on the relational angles of rights and ethics, and explicitly speaking the language of public and health – eventually coining the currently common and firm phrase indicating a distinct field of inquiry of public health ethics (Porter and Venkatapuram 2012; Kass 2004; Beauchamp and Steinbock 1999). Though bioethics continues to expand its thematic inquiry, some of the larger concerns with this field are the individualized orientation (obligations of physicians and protecting patients' rights, individual autonomy of research participants in biomedical experiments), overreliance on universal codes/guidelines and perhaps inadequate attention to societal and political arrangements that explain conditions conducive or obstructing health of the population. Speaking of the need for a "new ethics" for public's health, Beauchamp and Steinbook (1999:ix) argue how public health ethics must raise fundamental political questions including but not limited to "What is the meaning and scope of community and the balance between the market and the public realm in today's modern liberal society which is so highly individualistic? Does a strong public health policy require a rethinking of the current belief that the market ought to be dominant in most domains to assure an adequate standard of living for all and a high rate of growth?". Kass (2004) expands this line of thinking to state that in the current scenario of globalization, public health ethics must confront global public health and justice, thus asking questions about the role of national governments vis-à-vis the richer countries to the global poor, the data on health equity in alternative political and economic arrangements, role of global actors, and advocacy strategies to further global public health and justice. Feminist bioethics, in fact, has played an important role in offering a critique of the masculine generic "human subject" of bioethics and explicating the analysis of social structures, power, and gender in ethics (Rawlinson 2001).

Thus even as an offshoot of medical and bioethics, public health ethics has sought to establish a niche that emanates from the goal of public health emphasizing the population orientation of health (interrogating the public and health more critically), multidisciplinary orientation, and a more societal and political analytical lens to understand health, health inequalities, and outcomes. It has sought to not only reorient ethical lens but has expanded the nature of ethical inquiry to address the rather messy and complex issues in the public's health. The current climate of "continuing global need for public health action to address population-level health problems, the ongoing lack of public health infrastructures and poor environmental health in many places in the world, the growing health inequalities between rich and poor and growing health risks due to climate change, population movement, ageing, antimicrobial resistance and overconsumption" has only reinforced the growth of the public health ethics field of inquiry (Verweij and Dawson 2018:1). This distinctiveness however does not suggest exclusive boundaries between bioethics (and for that matter medical ethics) and public health ethics as many issues are overlapping. For example, the issues of antibiotic resistance and thinking of possible pharmaceutical innovations would be a theme for both these fields (Verweij and Dawson 2018). As Cribb (2010) argues, many such issues in the realm of bioethics need to be addressed through a public health lens.

Doing Public Health Ethics

Public health as a perspective and as an applied field cannot afford to engage with ethics in an abstract philosophical discussion of what is right and wrong. Public health practitioners are confronted with ethical issues and dilemmas in their everyday practice that need to be addressed and resolved and decisions need to be made that are clearly informed by ethical reasoning. Public health ethics is necessarily a field of applied ethics.

As discussed in the aforesaid sections, due to the nature of public health enterprise, the existing guidelines on medical and bioethics cannot simply be exported and applied. Further, public health practice involves a range of domains including policy making, program design, implementation, monitoring and evaluation, surveillance, research (using different research methodologies), communication, and advocacy. The boundaries between research and practice or policy and practice are blurred. Consequently international research ethics protocols have limited applications in these wide-ranging components of public health practice. In order to address these gaps, several frameworks have been developed to facilitate ethical analysis of public health issues (Kass 2001; Roberts and Reich 2002; Childress et al. 2002). For example, Kass (2001) offers a six-step framework that could help public health professionals analyze ethical implications of interventions, policy measures, program, etc. Childress et al. (2002), on the other hand, lay out moral considerations including effectiveness, proportionality, necessity, least infringement, and public justification as relevant to public health. While frameworks have certainly helped to build ethical thinking appropriate to public health, concern has been raised in terms of potential rigidity in trying to address myriad ethical challenges in different settings and contexts (Cribb 2010). In this regard, constructing a philosophically informed reflective framework has been proposed as one way of doing public health ethics (ibid). Four major philosophical frameworks have influenced the public health ethics discussions. These include utilitarianism (or consequentialism), liberalism, communitarianism, and more recently feminism (Roberts and Reich 2002; Cribb 2010; Holland 2015; Rogers 2006). These theories have been evoked to address some of the central issues in public health ethics around equity and effectiveness, individual rights/freedom vs community benefits. "The construction of this kind of philosophically informed framework for reflection on public health ethics is crucial to the development of the discipline. Without it, public health ethics degenerates into a trade in intuitions about health, freedom and community" (Cribb 2010:43). More recently, there has been sharper and critical engagement with these theoretical positions in eliciting nuanced applications of these principles and instruments in addressing ethical issues in public health policies and program implementation and evaluations (Brock 2004; Anand and Hanson 2004; Kamm 2004; Allmark et al. 2010; Holland 2015). Brock (2004), for example, raises ten issues around equity in the cost-effectiveness approach to allocation of resources informed by the utilitarian approach. These include pertinent issues around the standardized measurements like DALY (Disability Adjusted Life Year), QALY (Quality Adjusted Life Year) to ask if all QALYs count equally, what costs and benefits should count in cost-effective analysis of health programs, what priority should be given to the sickest or the worst off, the conflict between fair chances and best outcomes, etc. The efforts in these works have been to explicate the subtleties of ethical issues and challenges keeping in mind both the specific (efficiency, maximization profit, proportionality) and the broader ethical principles (equity, solidarity, rights and freedom) and potential conflicts that may arise in any specific situations among these principles (Brock 2004). Thus "… even if a consequentialist perspective was to be most prominent in public health ethics, it may well be pluralist and hence much richer than an all-too-simple focus on maximizing utility" (Verweij and Dawson 2018:1).

Another methodological discussion on doing public health ethics analysis is to ask how could the principles used in biomedical ethics including respect for autonomy, beneficence (obligation to act for the benefit of others), non-maleficence (an obligation not to inflict harm on others), and justice (fair, equitable) be helpful (Beauchamp and Childress 2001). While a straightjacket application of these principles is deeply problematic largely because of the nature of dilemmas in public health, it is also argued that public health would greatly benefit from adapting these principles (Upshur 2002; Cribb 2010). Upshur (2002), in this regard, adds the principles of reciprocity and transparency that can address some of the core tensions in public health in terms of obligations and responsibility of individuals and communities, processes of decision-making, and upholding procedural justice. Chapter 4 in this volume adapts the key principles in biomedical research to apply an ethical lens to the design of public health programs and successfully demonstrates such an adaptation.

Social sciences (specifically sociology, anthropology) have contributed a great deal in unpacking the interpretations and applications of ethical principles in health research (Harper 2007; Kleinman 1999; Desclux 2008; Riesman 2005; Posel and Ross 2014; Minocha 2013 to cite a few). This literature offers us two important lessons that are relevant to the methodology of doing public health ethics. Firstly, these strongly argue for an "ethics-in context" understanding and applications of ethical principles pointing toward the limitations of a standardized set of universal guidelines in international health research (that are suited for biomedical research). Research in several contexts shows how informed consent (evoked to respect individual autonomy and choice) has different interpretations. Speaking in the context of South Africa, De Varies and Henley (2014) argue how the decision-making process is based on discussions between people along different levels of social hierarchies with different kinds of relations to the participant and hence operationalizing the principle of autonomy (through informed consent) would require a contextual understanding. Informed consent in contexts of community-based research unfolds in different ways where community engagement and transparency (leading to the consent process) are imperatives (Harper 2007; Banks et al. 2013). The spirit of informed consent cannot be a regulated ethical mechanism but must be situated in broader values of trust, reciprocity, transparency, and accountability of the research process. Public health practice does not involve research alone not even one kind of research (epidemiological or biomedical). It involves several other components where the boundaries between these components are not categorical. Khanna (2015) elaborates the complexities of the interpretation of the four cardinal principles of bioethics in the context of community-based monitoring and planning (CBMP). Such a public health intervention that involves several stakeholders including government health system, facilitating NGOs, local communities and other networks, ethical issues about harm, risks, benefits, justice acquire different meanings as these concepts need to traverse through the dynamic and different sets of power relationships among these stakeholders. In community-based research, "who constitutes the community" is important to interrogate and reflect to operationalize any ethical principle (Madiwala 2009). Much of the attention to the "ethics in context" or "embedded ethics" emanates from different research epistemologies involved in health research. Ethical challenges drawing on from different research traditions and epistemologies are hardly discussed, while all forms of research in health willingly or unwillingly conform to the ethical approval following the dominant bioethical principles and increasing regulated ethics culture. The need for such conversations (though uneasy) within health research (public health/HPSR) is an imperative (Posel and Ross 2014; Desclaux 2008). The research process in bioethics assumes a certain form of sociality between researchers and researched – participants as the producers of knowledge. It thus ignores the fact that much of knowledge production happens in inter-subjective negotiations and the nature of research relationships is far from static (Harper 2007). In community-based participatory action research, where the boundaries between researcher and researched is blurred, ethical issues around partnership, accountability, collaborations, and community rights become critical than mere eliciting informed consent from individuals.

Secondly, increasing deliberations on ethics in public health research suggest that ethics is not about a one-off event of ethics approval. What is needed is "everyday ethics" which "stresses the situated nature of ethics, with a focus on qualities of character and responsibilities attaching to particular relationships (as opposed to the articulation and implementation of abstract principles and rules" (Banks et al. 2013:263). This is reinforced saying "We should bring the question of ethics – too often relegated to a one-off aspect of the research process to something that suffuses all we do as practicing anthropologists" (Harper 2007:2241). What is needed hence is not about how to take informed consent or how to resolve a specific dilemma alone but continuing deliberations on the ethical complexities among all those who have a stake in the process. Ethical issues are sometimes not even discerned (assuming that ethical approval necessarily renders the process of research, evaluation, or monitoring ethical) and when identified, are rarely documented, deliberated, and reflected. Posel and Ross (2014)'s book on *Ethical Quandaries in Social Research* beautifully demonstrates the value of critical reflections and resolutions of the messy tensions between and within guidelines, unpredictable nature of ethical issues that may arise during the course of research, and difficult choices one has to make between what is professionally required and what one does personally as an ethical human being. Through a first-person narration, the essays in this book drawing from different disciplines and research methodologies enrich our understanding of ethics, ethical dilemmas, and possible resolutions. There are collective resonances yet specificities depending on the nature of research theme, mode of research, research setting, and aspect of research. Thus doing public health ethics necessarily implies that it requires continuous reflections, deliberations, and resolutions (thus it is not about a one-off exercise of only seeking approvals for conducting research or eliciting informed consent) in every day practice of public health. Public health ethics requires greater sensitivity to people and contexts (public health necessarily involves a range of actors ranging from PRI at the local level to Global Health Initiatives at global level). It thus does not entail a straightjacket universal application of ethical guidelines rather a contextual understanding of its relevance through shared understanding and dialogues.

The Indian Context

Public health ethics as a field of inquiry is at a nascent stage in India. The traditional biomedical models of ethics have held precedence for a considerable period of time. A lot of attention has been devoted to the ethics of medical practice and obligations of health professionals (professional ethics). This has become critical in a context where 80% of the outpatient care in India is catered by the private sector. Thus corruption, over-prescription, overdiagnosis, and high cost of treatment leading to high out-of-pocket expenditure in seeking health-care services in the private health sector (accompanied by a crumbling public health system and weak regulation of the private sector) have been brought to the fore as the moral failure of the Indian health sector (Barua and Pandav 2011; Gadre and Shukla 2016; Mazumdar 2015; Nagral 2014; Sengupta and Nundy 2005; Barik and Thorat 2015; Ghosh 2011 to name a few). While India certainly has had its successes in terms of increase in life expectancy, eradication of small pox and more recently polio, and reversing the incidence of HIV/AIDS, the health of the population is marked by persistent inequities by region (rural/urban, different states), religion, caste, class, gender, and ethnic communities (Sundari and Gaitonde 2018; Baru et al. 2012; Balrajana and Selvaraja 2011; Sen et al. 2007). The WHO Commission on Social Determinants of Health and the rich literature in social science indicate that it is not availability of health care but structural determinants of health including bad politics, poor policies, and unfair economic arrangements that explain such inequities (WHO 2010). Economic/political and social arrangements that prioritize and promote (or inhibit) health, as Beauchamp and Steinbock (1999) suggests, are at the heart of public health ethics. The developmental model in postcolonial India has privileged industrial/economic growth for a long time neglecting investing in social sectors including education and health landing itself in a situation of "uncertain glory" as Drez and Sen (2015) term it. The role of the developmental state becomes important in a context where health is not a constitutionally mandated right. The increasing role of the private sector and the more individualized model of health care (depending on ability to pay) have not been a coincidence but a result of long neglect of the public health system (Rao 2017). With a burgeoning for profit private sector, engaging with them meaningfully in national public health programs hence continues to be critical (Hess et al. 2010; Udwadia et al. 2010; Uplekar et al. 2001).

India is home to more than 30 disease control programs, the implementation of which is inconsistent across states and fraught with challenges. While many of these challenges are dubbed as implementation failures, it is argued that an ethical lens is warranted in order to strengthen the impact and outcome of the Revised National Tuberculosis Control Program (RNTCP) (Porter and Ogden 1999; Babu et al. 2014; Ogden et al. 1999; Narayan 1999; Zachariah et al. 2012). These studies have considered a number of issues including the language (control, defaulters, and its implication) used in the program, methods of case detection and estimation of prevalence and incidence, delimiting lens of a biomedical model of controlling the disease, need for an equity lens to understand burden and access, importance of the cultural context in the experience of diseases, and accessing treatment as well the larger political context where RNTCP is located within an otherwise under-resourced public health system and its implications. As stated earlier, this is one of the early programs where the role of private sector has been seriously considered and experimented upon with mixed experiences (Pradhan 2011; Dewan et al. 2006; Kielmann et al. 2014). While discussions on ethical issues on few programs like RNTCP and immunization have received attention, it is increasingly being acknowledged that an ethical lens to the framing/design, implementation, scaling up, monitoring, and evaluation of public health programs is an imperative. While the traditional bioethical principles can be adapted, the ethical inquiry needs to be extended as discussed in Chap. 3 in this volume and in other studies (Khanna 2012, 2015; Gopichandran and Chetlapali 2012).

One of the key public platforms for discussion on ethics that has arisen over the past decade is the in-country series of collaborative National Conferences in Bioethics (NBC). These conferences have been instrumental in bringing together individuals and institutions with varied interests, perspectives, and engagements in both the biomedical and public health sectors within India, along with students and young professionals. As stated in the first national conference in 2005, the rationale of the NBCs is "to give a platform for the various debates in the ethics movement within the country and to give an impetus to the process of scaling up of the nascent bioethics movement" (Ramanathan et al. 2006:27).

Some of the subjects these conferences have brought into focus over the last 10 years are reflective and indicative of the necessary attention health ethics has gained in the country. The *Indian Journal of Medical Ethics* (IJME) has hosted these National Bioethics Conferences since 2005 with subnational collaborators and partners. IJME continues to be a journal and portal that discusses several emerging aspects related to what can traditionally be defined as medical ethics as well as that of bioethics. The themes in the NBCs series have ranged from ethical challenges in health in an era of globalization, moral and ethical imperatives of health-care technologies, governance of health care, ethics and regulatory challenges in health research, integrity in health care and research, etc.

These efforts have been pioneering in the spotlight they threw on the need for a more synchronized and informed ethics movement in the health sector. Also, for the first time, it brought together a very diverse set of professionals within the field of health such as educators, researchers, academics, health-care providers, program/project managers, and implementers from various organizations across the country. The Centre for Studies in Ethics and Rights (CSER) under the Anusandhan Trust commenced the same year (2005) when the NBC series began. The CSER was set up to provide a long-term research program in ethics first as an independent center and subsequently as a part of the trust itself. Between IJME journalistic and conference-based efforts and CSER, there has been real progress in bringing the subject of bioethics to the discussion table among health practitioners. However, while both efforts have made significant contribution to bioethics, the focused attention on the ever-expanding list of issues within public health ethics still has much to be desired. While several ethical dilemmas in public health ethics are considered in these efforts, their objectives tend to focus on health-care provision and providers, health research, and agendas. While in many ways these subjects continue to form the fulcrum of the debates, the time has come for concurrent concentration on the wider net of ethical inquiry public health necessitates. For this, we need forums that would do the same for public health ethics and practice with greater engagement of social science disciplines. What is also critically missing are the discussions on pluralism (as a value and practice) and the ethical issues at the construction of evidence, efficacy, mainstreaming, revitalization of "traditional" systems of medicine and community-based health knowledge, and their practitioners. The last quarter of 2018 will see the 14th World Congress of Bioethics being held for the first time in

India. The “Health for All” theme in the conference is indicative of the conscious steps toward universality and integration in the Indian health scenario. As it is of the change, the bioethics movement has sparked for a more constructive integration between public health ethics and bioethics movements and practitioners. Large-scale and transnational future forums such as these will be pivotal both for locating, planning, and executing new directions in ethical inquiry and engagement in all aspects of public health practice. Some of the interesting discussions around ethical issues at the intersections of bioethics and public health ethics have come from feminist scholars. Their work on commercial surrogacy, family planning program, reproductive rights, and evaluation of women’s health programs has enriched the discussion of public health ethics (Sarojini et al. 2015; Sarojini and Bhagianadh 2017; Khanna 2012; Khanna and Subasri 2014). Feminist approaches have sought to reorient bioethics to engage with gender and power in more nuanced ways.

There are silences on the ethical dilemmas and challenges in public health more by default than by design. While most practitioners face ethical dilemmas routinely in their work, the tendency is to respond on a case-by-case basis and with the aid of informal in-house consultations and deliberations due to several constraints. The reasons for this are more often practical. Time and resource constraints, dearth of easily accessible venues for collaborative dialogue, lack of standardized guidelines, applicability of adapted guidelines, and institutional restrictions often determine transparent consultation. These silences indirectly create inconsistencies in the development of institutional protocols, few opportunities to share what could be of significant relevance to each other, fear factor to consequences, and a reactionary rather than a proactive set of skills in routine public health practice. A practitioner can move to a role of enablement only when there are open recourses to identify and articulate gaps in providing that support to others. It is imperative that such expressions can occur without apprehensions of adverse consequences to oneself, one’s capability, and one’s practice. The availability of authentic and transparent mechanisms to break these silences will create more empowered spaces for ethics to permeate all processes and outcomes of public health practice.

Recently the need for integrating ethics into the public health education programs has been strongly felt. While the number of public health training programs and institutions continues to expand, a survey of the curriculum and pedagogy of these programs shows that ethics training is sorely missing (Pati et al. 2014). Ethics cannot be reduced to a module alone but must be integrated explicitly and intentionally to the curriculum; further, the training of public health ethics can not be limited to medical professionals. Public health encompasses a large number of stakeholders, and capacity-building programs need to reach out to these varied stakeholders. Innovative programs are the need of the hour to impart such training so that both young professionals and those in-service professionals could benefit from such a training. Chapter 10 in this volume discusses what kind of curriculum and pedagogy might help to nurture an ethical lens to public health practice.

Way Forward

Rothstein (2012:27) in an editorial titled “The future of public health” succinctly concludes “As long as society needs public health, it will also need public health ethics to identify the interests at stake, weigh alternatives, consider consequences, and help ensure that the benefits and burdens of public health interventions are distributed equitably across society”. Public health ethics, as the chapter discusses, is distinct though sharing a historical legacy with medicine and bioethics. The distinctiveness emanates from the goals of public health and the nature of the academic field of inquiry (necessarily multidisciplinary) and practice that includes research, policy making, program design, implementation and evaluation, screening, surveillance, advocacy, and communication. As Beauchamp and Steinbock (1999) state, doing public health is not a technical activity, but it is about doing social justice. Ethics hence is at the heart of what we, as public health practitioners, do. Ethics in public health practice liberates itself from both a purely philosophical engagement with ethics and prescriptive and regulatory nature of ethics (assuming it to be the prerogative of the ethics committee experts). This has made ethics discussion isolated and fragmented. In fact, ongoing research and practice in HPSR has important contributions to make to the discussion of public health ethics, but at this stage it is yet to be integrated into this discussion. Public heath ethics demands ethics of the everyday practice and by all practitioners. The methodology of doing public health ethics demands a critical and reflective lens in the everyday practice that is continuous and resolved through individual and collective deliberations. Careful training programs hence need to be designed to address such demands of public health ethics. While select efforts are already underway in different contexts, India is yet to catch up. The last decade or so has witnessed an explicit engagement with public health ethics in outlining its imperative and the nature of inquiry; this chapter (along with the book) is a modest contribution to this conversation. It has an added significance in the context of India which is at a cross roads of sitting on its “uncertain glory” with consistent economic growth with inequitable health outcomes. If India is committed to create conditions for production of health and healthy communities, ethical considerations would go a long way in such an enterprise.

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Chapter 2
Public Health Rights and Ethics: Conflicts, Contestations and Expanding Horizons

Edward Premdas Pinto

Abstract This chapter seeks to critically address the interface of ethics and public health rights. The dialectics of the interface of public health rights, interchangeably used as social right to healthcare (SRHC) and ethics, are marked by dilemmas, conflicts and contestations. The constitutional ambiguities in the articulation of SRHC on the one hand and the crisis of public healthcare on the other have further confounded such ambiguities that have resulted in gross systemic and individual violations of citizens' dignity and wellbeing. This paper aims to (1) introduce the concept of rights in relation to ethics in public health discourse; (2) familiarise with the debates, dilemmas and contestations in the interface of rights and ethics; and (3) broaden the horizons of ethical framework in practice. The efforts of the civil society in India in foregrounding such ethical-moral argument are used to exemplify and argue for the dimension of social citizenship and rights as an inviolable constituent of the emerging public health ethics. Such terrain, however, is beset with challenges with contestations, dilemmas and conflicts, even as it is dynamic and ever expanding.

Introduction

Why do we need to speak of rights alongside ethics *in* and *of* public health? Is there a right to public healthcare? How do rights and public health/care relate to each other? How and where is ethics located in this interface? These questions are central to discussing the interface of public healthcare and rights, specifically in the context of India.

Ethical analysis of public health practices has highlighted the paradoxes and ethical dilemmas that public health practice encounters. These include perspectives between liberalism and egalitarianism, approaches of utilitarianism and individual specificities or those which are universal and relativist (Roberts and Reich 2002).

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The strong relationship between ethics and public health and their linkages with global health and justice have already been substantially discussed (Callahan and Jennings 2002; Childress et al. 2002; Kass 2004). This chapter focuses on public health practice from the perspectives of the constituents that form the goal of public or population health, namely, health and wellbeing of citizens and communities. Such arena of interface wherein ethical dilemmas, conflicts and contestations exist depicts an unequal exchange of power between public health as a discipline and system of health services – often paternalistic and patronaged by the power of the State and its intentions – and citizens/communities frequently unguarded and unprotected in the process of seeking or accessing public healthcare services. Foregrounding ethics in such an interface, this chapter intends to (1) introduce the concept of rights in relation to ethics in public health discourse; (2) familiarise with the debates, dilemmas and contestations in the interface of rights and ethics; and (3) broaden the horizons of ethical framework in public health practice.

The scope of public health is wide and undefined and includes various social-economic-cultural-political dimensions of policies and practices. The frame of reference for discussion in this paper is limited to allopathic healthcare/services (preventive, promotive, curative and rehabilitative) accessed by the ‘public’ and includes both the State and privately provisioned services. Section one on social citizenship, rights and ethics discusses the theoretical framework of social citizenship as foregrounding public healthcare and rights; Section two on systemic dimensions of public health rights discusses the dual dimension of public health rights, viz. social arrangements for healthcare and the balance of power in a triadic relationship of the State, healthcare providers and citizens; in Section three the crisis of public healthcare and rights is discussed in the context of India; and the last section foregrounds the critical edge of ethics to navigate through the contestations, dilemmas and conflicts in such socio-political contexts as that characterise India.

Social Citizenship, Rights and Ethics

Rights and Ethics

The ideas of citizenship and civil society have been central to the modern political thought, indispensable to the concepts of social rights, and together they bring into focus the relationship of the individual with the State (Turner 2000). Rights and duties and legal, social and political entitlements form the core of citizenship content. Citizenship denoted here, nonetheless, is not limited only to the legal citizenship of a nation-State but encompasses a multidimensional perspective – viz. democratic (Stewart 1995), civil-political and social citizenship (Marshal and Bottomore 1992). Democratic citizenship refers to a shared membership of a political community, civil liberties element relates to the individual freedom, and the political component is indicative of the participation in the exercise of political power. The dimension of social citizenship is much broader and includes the whole range ‘from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilized being according to the standards prevailing in the society’ (Marshal and Bottomore 1992:30).

In feudal societies as well as in authoritarian regimes, people are considered beneficiaries or subjects. It is only in the context of liberal democracies the idea of citizenship exists and that rights can be spoken of. However, even in democracies such as India, the power asymmetry between citizens and other actors continues despite the policy articulations and legal provisions, which compromises and limits the power and rights of citizens. In several arenas of social rights, as that in healthcare, such constitutional or policy provisions do not even exist, and often laws and constitutional frameworks fail citizens due to their inadequacies and gaps, compelling citizens to agitate for such provisions. Citizenship, therefore, is conceived as active and dynamic and denotes citizens as active political actors (Turner 1990:221, 2000). The framework of rights, therefore, foregrounds itself as the medium through which citizens express their claim to citizenship, resist the overpowering State and other actors and stake their claim for equality and dignity. The framework and concepts of rights that are fundamental to citizenship originate in the ethical-moral discourses. This paper argues that ethics forms the foundation of rights and, in their interface, holds the balance of power in advancing social citizenship.

Social Right to Health and Public Healthcare

The discourse on rights identifies at least five different types of rights: personal rights (life, liberty, security, property, conscience); legal rights (due process, equal protection under the law); political rights (participation, suffrage, assembly); social and economic rights (standard of living, employment, healthcare, education, nutrition); and collective rights (ethnic self-determination, minority rights) (Gauri 2004; Gauri and Brinks 2008). Rights are also categorised as negative rights and positive rights. Negative rights are those where the State is restricted from interfering into the personal liberties of individual human lives, and the positive rights call for a proactive intervention into providing social rights to citizens. Health and healthcare belong to the genre of positive rights. Summarising the debates, Gauri (2004:467) argues that fulfilment of all rights, especially the social rights, require ‘protection and aid from the entity from whom rights are claimed, and that a reasonably effective and well-funded state is a *sine qua non* for all rights’.

The idea of social rights which includes public healthcare is an integral component of the social citizenship. They imply ‘an absolute right to a certain standard of civilisation which is conditioned only on the discharge of the general duties of citizenship’ (Marshal and Bottomore 1992:36). The closest interrelationship between citizenship and public healthcare can be traced to social rights theories which became one of the core themes in the post-war Keynesian construct of a welfare State. During the mid-twentieth century, in the post-depression era, the Keynesian model provided a theoretical framework to the idea of welfare

State. Healthcare is conceptualised as a social right and an inextricable component of social citizenship. Redden (2002:356) elaborates the close association of healthcare and citizenship narrative:

> It is undeniable, however, that health care is relevant to citizenship and is often debated in the language of rights. The tension or balance between individual liberty (rights and freedoms) and collective welfare is the substance of citizenship. Thus, health care (as distribution, provision, and access) is an issue of citizenship.

Public health including healthcare closely relates to the dimensions of social citizenship, and it binds the ideas of public health aimed at the wellbeing of populations and rights of citizens. However, as a discipline, public health itself is often expert led and tends to be technocratic and follows a top-down model of decision-making. With such an approach, the State exhibits its paternalistic character, and citizens are often rendered passive entities divested of citizenship, as demonstrated in the Poor Law in England, for example. The Poor Law treated the claims of the poor, not as the integral part of the rights of citizens but as an alternative to them – as claims which could be met only if the claimants ceased to be citizens in any true sense of the word which is called 'divorce of social rights from the status of citizenship' as it was extended to women, destitute and paupers who were not considered citizens (Marshall and Bottomore 1992).

Public healthcare itself, therefore, has the propensity to be the contested terrain for compromising citizens' autonomy and agency in decision-making and participation. Ethics, thus, attains centrality in our discourse as arguing for the active and dynamic social citizenship, which respects autonomy of the citizen. Conceptually, while the ethics framework provides the ground to challenge the paternalistic yet hegemonic approaches of public health which tend to violate citizenship rights, operationally public healthcare as a social right can only be available to citizens as a mechanism embedded in the State policy. Institutional perspectives lend themselves to further unpack the contours of public health rights and their interface with ethics in the process of realising SRHC.

Systemic Dimensions of Public Health Rights

Public healthcare is about distribution, provision and access to healthcare services, and such a systemic dimension is inherent in the very understanding of public health as a discipline which is defined as organised efforts as a society to ensure conditions for people to be healthy.[1] While conceiving public healthcare as a social right, ethics perspective outlines the dual dimensions of this right, viz. establishment of an

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[1] Institute of medicine defined public health as "what we as a society do collectively to assure the conditions in which people can be healthy" (IOM 1988); Turnock (2001) described public health as the "collective effort to identify and address the unacceptable realities that result in preventable and avoidable health outcomes, and it is the composite of efforts and activities carried out by people committed to these ends" (Noland 2004).

accessible public healthcare system and balancing the unequal power relationship by empowering health-seeking citizens, who are otherwise vulnerable vis-à-vis the healthcare providers and medical profession.

Social Arrangements for Health and Healthcare

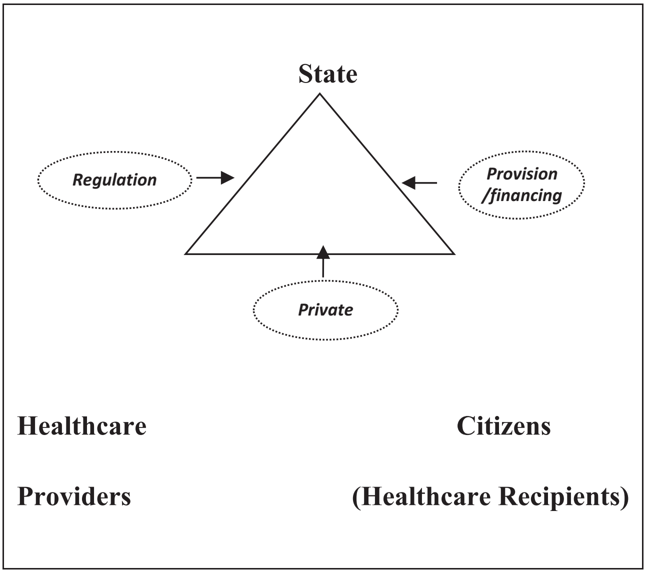
The Alma Ata Declaration in 1978 played a pivotal role in bringing the idea of human rights into health and healthcare for the first time to provide a healthcare vision which encapsulates the human rights perspective. It positioned health as part of the development paradigm addressing the root causes of diseases in the social conditions. In addition, it also proposed primary healthcare as fundamental to human wellbeing and emphasised for universality and a set of social arrangements for its availability (WHO and UNICEF 1978). Alma Ata Declaration embodies such an integration of approaches and provides the primary health as the most basic social arrangement of services. The World Health Organisation (2002) too endorsed such an understanding of right to health as a ‘claim to a set of social arrangements - norms, institutions, laws, and an enabling environment’ (p.11).

The International Covenant on Economic Social and Cultural Rights (ICESCR) provides the operational and legal framework for such a social arrangement of healthcare services as an inclusive right ‘to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable standard of health’ (UNOHCHR – CESCR 2000: Sects. 8, 9 & 11). Specifically, concerning the public healthcare, General Comment 14 lays down the principles for a system of healthcare organised based on the principles of availability, accessibility, affordability, appropriateness and quality (Gen Comment 14).

Public healthcare with its inherent paternalistic outlook and the technocratic power can potentially circumvent citizenship. Ethics perspective buttresses citizenship by reinforcing that such social arrangements of public healthcare are delivered not merely as services but primarily packaged as rights of citizens. Public healthcare system, thus, can be viewed as the canvas which provides for the interface between citizens and the State or healthcare providers serving as the fulcrum of balancing power where the citizens’ autonomy, dignity and rights are protected, respected and fulfilled.

Public Health Rights as Balance of Power

Unlike a civil-political right, public health or healthcare is not a matter between citizens and State alone. Public healthcare involves a complex relationship between plurality of actors (such as medical profession and multitude of healthcare service providers), hierarchies of healthcare and policymaking and implementing institutions and an interface of the individuals with these institutions and providers.



(Source: Adapted from Gauri and Brinks 2008:10)

Fig. 2.1 Institutional relationships in public health rights. (Source: Adapted from Gauri and Brinks 2008:10)

The social citizenship foregrounded in SRHC or public health rights is a triangular complex relationship between the State, healthcare providers and citizens. Figure 2.1 depicts the social citizenship navigated through the duties of various actors and liberties and rights (social and economic rights) that arise for the citizens (Gauri and Brinks 2008). Interface of three sets of actors, viz. State, healthcare providers and citizens (clients or patients, in the context of seeking healthcare), is the key to understand SRHC. Each of the three key actors is constitutive of a plurality of actors such as individuals, institutions, professional associations, government service delivery systems and administrative bureaucracies located at various levels of the central and State administrative jurisdictions. Similarly, the healthcare providers include a range of professionals, professional associations, private hospitals, charitable institutions and corporate healthcare, diagnostic entities, corporate business entities in healthcare, insurance providers and so on. Of all the actors, it is the medical profession, which is an absolutely critical actor in the realisation of SRHC, due to the critical power it wields in medical care. The citizens seeking healthcare are overburdened with the onus of personally manoeuvring and negotiating both with the State for claiming their health entitlements when they face challenges such as medical negligence or face adversities at the hands of the healthcare providers. This is because of the fact that the right to healthcare and the mechanisms of delivering such rights are not constitutionally defined nor legally protected vis-a-vis the State. The liabilities of healthcare providers are not legally defined (e.g. patient rights) in relation to the healthcare providers, most of whom are now located in the predominantly unregulated private healthcare sector).

The relationship between the State and healthcare providers is expressed in terms of regulation. In the absence of a singular regulatory authority, the varied issues of regulation are operated by diverse authorities employing varied measures (Ayres and Braithwaite 1991; Healy and Braithwaite 2006; Makai and Braithwaite 1992; Sheikh et al. 2013). The relationship between the State and citizens is established through the role of the State in healthcare provisioning, resource allocation/financing and production of human resource for health.

A third dimension is exhibited by the relationship between the healthcare providers and the citizens. Medicine focuses on treatment and cure of individual patients, and physician-patient relationship is at the core of medicine or healthcare (Childress et al. 2002). Medical profession and practitioners are seen as professionals and exponents of different types of power. It is expressed in the control of medical profession (Gilson and Raphaely 2008; Friedson 1970). Similarly Illich (1977) argued that the doctor's power of discourse over illness serves as a means to perpetuate their own interests. The medical practitioners tend to employ 'negative power' of resistance against any regulation and also lack positive power of intellectual capital and of contributing to policy process (Sheikh and Porter 2010).

This dimension is contentious, hardly defined by any policy, and consequently is treated as a private law relationship in the domain of courts. In accordance with this understanding, State does not interfere in these matters, and citizens themselves are bound to enforce these obligations and are considered as private obligations. The SRHC and its realisation will finally rest on the duties and liberties that extend between healthcare providers and citizens (clients). These include patients' claim for compensation under law of tort, duty of the healthcare providers to safeguard confidentiality, obtaining informed consent prior to the treatment and ethical and moral requirements for medical practitioners to treat certain class of patients such as rape victims, etc. Institutionalising rights of citizens, guaranteed through constitutional and/or legal provisions, play a crucial role in such a balance of power. In the triadic relationship of actors conceptualising health justice, citizens seeking healthcare are the most powerless entity as compared to the State and the medical profession. From an institutional and power perspective, health rights can be conceived as balance of power through institutional rules. Young (1990:25 cited in Gauri and Brinks 2008: 13) proposed that 'rights are not possessions but institutionally defined rules specifying what people can do in relation to one another'.

SRHC is not a right to set of properties, goods or services alone. It is redefining the relationships of citizenship which will govern the enjoyment of the goods or services. It is a claim to change the rules that govern the production and distribution of all goods, services and relationships of healthcare. It is also establishing institutional mechanisms and procedures by which the goods and services related to healthcare can be redistributed equitably, which can be better described as health justice.

The claim to such a balance of power and the citizenship narratives in healthcare have emanated largely from ethical-moral arguments of human rights, healthcare as a special social good and as integral to social justice.

- *The foundations of healthcare as a fundamental human right:* The relationship between a health service provider, primarily a doctor, and an individual (patient) was characterised as a contract, and violations of such contract were redressed using the law of contract and torts (Teitelbaum and Wilensky 2009). Beyond the legal framework, human rights provides the ontological foundations for grounding of right to health and healthcare as integral to the protection and promotion of human dignity and ethics (Chapman 2015). Human rights articulate the scope of SRHR as 'the highest attainable standard of health' and set down its character as being made available to all without distinction of race, religion, political belief, economic or social condition (UNOHCHR 1948:Article 25; UNOHCHR 1966:Article 12;WHO CSDH 2008).

- Mann et al. (1999) cogently articulates the mutually reinforcing dimensions of public health and human rights, signifying their linkage, intersectionality and overlapping boundaries. Historically medical ethics provided important grounding for right to health initially; there is now a need felt for firmly considering ethics *in* and *of* public health (Ruger 2006; Kass 2001, 2004). Human rights outlines not only an ethical-moral framework for public health rights but also provides the legal framework in the international human rights law that enables the identification of the barriers and violations that exist in the design or implementation of health policies to the detriment of wellbeing of citizens. Besides, it also provides a tool to articulate these violations such as the discrimination against ethnic, religious and racial minorities, as well as exclusion of citizens on account of gender, political opinion or immigration status from the benefits of social rights or those factors that compromise or threaten the health and wellbeing of large number of populations.
- *Healthcare as a special social good:* Health along with education is considered as fundamental to exercise human agency as ill-health (disease) and ignorance (lack of education) are argued to be barriers that deter human beings from exercising agency to live a fully human life. Such basic requirements are explained by Rawls (1971, 1999, 2001) as 'primary goods' and in Shuhe (1996) as 'basic needs'. Similarly Nussbaum (2000) and Sen (1980, 1982) explain it through the concept of 'capabilities'. Social rights, especially the right to health (and education), are justified and argued for also on the philosophical ground of 'human dignity'. Social right to health is essential to live with human dignity in the modern and contemporary society, without being excluded from others and to relate to fellow human beings. John Rawls formulates 'self-respect' as one of the core primary goods, and health (and education) are construed as the social bases of such a self-respect (1971, 2001).
- Structural inequalities, unequal health outcomes and consequent health inequalities being a limitation on enjoying full citizenship are being analysed from considering health and healthcare as being different from other goods, and hence

their deprivation offends people more than other goods. Societal inequalities and disparities undermine people's capacity to function as free and equal citizens (Daniels et al. 2004) leading to ill-health furthering jeopardising the realisation of human capabilities (Sen 1999). Inequalities in health are integrally linked to and are constitutive of people's capacity to function (Anand et al. 2004). Ethics perspectives and concepts such as 'fairness in equality of opportunity' (Rawls 2001; Scanlon 1973) and 'freedom and capability' (Sen 1999, 2002, 2004) have augmented the argument of healthcare as a special social good needing special political and economic consideration.

- *Healthcare is an integral part of social justice:* Ethics and social justice scholarship has proposed healthcare to be considered 'a special social good' and an integral part of equity and distributive justice (Daniels 1981). Among the classification of justice domains, viz. retributive justice (related to punishment of crimes), compensatory justice (relating to compensating victims of wrongdoing), and distributive justice (relating to sharing benefits and burdens), it is the latter two that closely intersect with the idea of social justice (Winthrop 1978). Distributive justice in public healthcare or conceptualising healthcare as part of the justice framework envisages equitable distribution of healthcare infrastructure, services, healthcare professionals, resource allocation and the protection of the rights of patients as well as various providers. Rawlsian framework of 'fairness in equal opportunities' leads to providing a fair opportunity for every citizen, in an equitable manner, to access healthcare and to have a fair chance to enjoy happiness and wellbeing. The legal provisions for such a distribution would be necessary but insufficient. The element of dignity and justice will be realised only when the possibility of an equitable society and the equitable distribution of societal resources will happen.

With these critical perspectives, the next section will delve into the interface of ethics and public health rights in the specific context of India.

Crisis of Public Healthcare and Rights in India

The analysis of the policy and operational contexts of healthcare in India strongly allude to twin aspects of this crisis in public health rights, namely, the crisis of public healthcare system and the crisis of right to SRHC (Desai and Chand 2007; Qadeer 2011b; Qadeer & Council for Social Development (India), 2015; Rao 2005). These crises make a compelling argument for the vital role of public health ethics in India.

The earliest discussions on the SRHC in the early 1990s emerged in the backdrop of crisis of healthcare putting an uneven burden on citizens through out-of-pocket expenditure. This is a paradox even in the advanced economies such as the USA (Roemer 1989; Chapman 1994; Mann et al. 1994, 1999). Such discussions foregrounding the crisis of healthcare to a large number of indigent and poorer populations pitch in to argue for healthcare as at least a 'quasi-public good' to counter-positioning healthcare as 'market good'. It argued for universal financial access to health insurance[2] (Karsten 1995).

Constitutional Ambiguity and Lacuna of Legal Protection

India does not have a well-articulated, constitutionally founded and direct social right to healthcare in India. Social right to healthcare is ambiguously located in the Constitution of India and is not a legally protected right in India. In India, the references to public healthcare are derivative and indirect. The Constitution of India reflects the contents as well as the spirit of the Universal Declaration of Human Rights. However the debate and divide between civil-political and social rights are inherent in its structure. The former are incorporated in Chap. III of the Constitution as justiciable fundamental rights, while social rights which is an umbrella covering SRHC are addressed indirectly by the Constitution and are broadly covered under different sections of the Directive Principles of State Policy (DPSP).[3] The latter are nonjusticiable rights subject to progressive realisation. This division has serious implications with respect to the justiciability of social rights in general, including one of the most essential – the human right to the highest attainable standard of health, including preventive, curative and rehabilitative medical care. The closest reference to healthcare as articulated in Article 47 of the Constitution of India recognises the 'duty of the State to raise the level of nutrition and the standard of living and to improve public health'. Despite several judgements which have laid down that healthcare is a fundamental human right, it has not impacted substantial constitutional amendment to give effect to such jurisprudence.

The socio-political context of India, the constitutional scheme and the design of the judicial system pose a composite challenge to the recognition of and redressal of SRHC violations. There is a lack of recognition and constitutional expression of the SRHC as it has been done in some of the modern constitutions.[4] The expression of public health and healthcare are patchy and are relegated to Chap. IV as incohesive

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[2] Subsequently, discussion on universal insurance and an adequate legal framework began in the early 1990s, to be realised as Affordable Care Act (known as Obama Care), only after 15 years (Jaffe 2012). The republicans again have started the process of whittling down this Act by tabling amendments in 2017, indicating the political nature of SRHC of the marginalised.

[3] 39 (e) 'health and strength of workers (...) are not abused ...'; 39(f): 'that children are given opportunities and facilities to develop in a healthy manner..'; Article 41: '... securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement...'; Article 42: 'humane conditions of work and for maternity relief'; Article 43: 'conditions of work ensuring a decent standard of life...'

[4] In South Africa's constitution, for example, Sect. 27 on healthcare, food, water and social security states (1) everyone has the right to have access to (a) healthcare services, including reproductive healthcare (Constitution of South Africa 1996).

pieces, subjected to the limitation of nonjusticiability imposed by Article 37.[5] Consequently, a number of issues on health policy, allocation of budgets, adequacy of health programmes, the accountability of the healthcare system (including the private healthcare system) and the duties and obligations of the State are without any consistent constitutional direction. Besides, in the federal structure of the Indian State recognised by the Constitution, public health and healthcare are classified as State subjects, which makes cohesive policymaking a challenging task.

The relationship between the constitutional articulations on SRHC and guaranteed healthcare is ambiguous. Having an articulation of SRHC in the constitution and in law is distinctly different from the State's policy on public healthcare and public spending on healthcare which is essential for the realisation of SRHC. The research of Eleanor D. Kinney (2008) shows that 68 percent of countries have some articulation of right to healthcare varying from having the intention of SRHC to providing for an affirmative duty on the State to provide care. Her research indicates that countries showing greatest constitutional commitment spend less than half as much per capita on healthcare compared to countries with no formal constitutional declarations on right to health and healthcare. Several multi-country studies on social rights indicate that having a legal framework accentuates the possibilities for citizens to articulate violations and stake claims for their rights.

Crisis in the Public Healthcare

Healthcare in India is currently in a critical state brought about by many years of systematic underinvestment in the public health sector, lagging far behind comparable countries such as Brazil and China. India already had a very low state investment in healthcare in 2004, which even after combining central and State spending was less than 1% of the GDP (gross domestic product). The private contribution to healthcare expenditure in 2004 was over 80%, most of which was out-of-pocket expenses, pushing millions of people into poverty. The low investments in health budgets led to erosion of public health infrastructure and an inadequate health workforce with extremely poor training.

The National Rural Health Mission (NRHM) in 2005 was launched in the backdrop of the iniquitous distribution of health services in rural areas as compared to the urban areas and was expected to strengthen the rural health services. However, even after a decade of NRHM which eventually was renamed as National Health Mission (NHM) in 2014, extremely uneven picture of health facilities across India, especially the EAG (Empowered Action Group) states, continues.[6] NRHM in 2004 aimed at

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[5] Article 37 states: 'The provisions contained in this Part shall not be enforceable by any court, but the principles therein laid down are nevertheless fundamental in the governance of the country and it shall be the duty of the State to apply these principles in making laws'.

[6] The eight states with the poorest health indicators, namely, EAG states (Uttar Pradesh and Uttarakhand, Madhya Pradesh and Chhattisgarh, Bihar and Jharkhand, Orissa, Rajasthan) and

reducing the high costs of healthcare resulting from low public health financing (NHSRC 2016). The out-of-pocket expenditure (including household payments for private health insurance) as a percentage of total health expenditure is still high at 68% [7] (NHSRC 2016). Public health spending continues to be extremely low in India at 1.2% (combined for centre and States) of the GDP which ranks India 143rd among 190 countries, among the lowest in the world (Parliament of India 2016, para 2.10).[8] A starved and enfeebled public healthcare system is the fertile ground of the violations of human rights of citizens and a setback for their claim to citizenship.

This neglect of the public health system contributed to the growth of a flourishing but unregulated private health sector. The State is increasingly seen to be abdicating its constitutional responsibility for the healthcare of citizens. The increasing privatisation, downsizing of the provisioning role of the State, non-regulation of the expanding private-corporate healthcare sector and unaccountability of the medical profession which is increasingly seen to be involved in unethical practices in promoting the profiteering logic of corporate healthcare lend credence to such an observation. In the wake of policy gaps and a weak political will to protect the SRHC of citizens, civil society has used the core arguments of ethics to press for right to healthcare as the fundamental right in India.

In India, various governments have pushed for healthcare as a business through unstated policy intentions, confusingly couched language in the policy documents, especially in the post-liberalisation era (Baru 2001, 2005). The National Health Policy has used the language of health assurance instead of health rights. Similarly,

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Assam (DLHS-4-IIPS 2014). The sub-health centres (SHCs), primary health centres (PHCs) and community health centres (CHCs) are the backbone of citizens' access to public healthcare in India. However, even in 2016, crucial infrastructure remains incomplete despite the additional support of the NRHM: there is a shortfall of 35,110 SCs (20%), 6572 PHCs (22%) and 2220 CHCs (30%) across the country as per the rural health statistics (RHS) 2016 (http://nhm.gov.in/nrhm-components/health-systems-strengthening/infrastructure.html, seen on April 28, 2017). The shocking lack of specialists in CHCs has been marked in the rural health statistics (RHS) 2016 as a 'huge shortfall' of 83% physicians, 84% surgeons, 80% peadiatricians and 77% ob/gyn doctors. A functioning OT is available for around half the CHCs in UP, MP and CG and even less in Rajasthan and Orissa, while for Assam only 13% CHCs have a functioning OT. Assam has blood storage in 23% of its CHCs, and Rajasthan comes a distance second at 13%. In all other states with high rates of MMR, the percentage of CHCs with blood storage ranges from 2% (UP) to 8% (Orissa).

[7] In fact out of 192 countries ranked in terms of out-of-pocket expenditure as a percentage of total health expenditure in 2014, India is placed at 183 just above neighbouring countries of Bangladesh (187 rank) and Afghanistan (184 rank).

[8] According to the National Health Accounts 2013–2014 (NHA), the government share of the total health expenditure has gone up only from 23% to 29% in this decade. The union government spends Rs 358 per capita for healthcare, while the State governments and union territories/local bodies spend Rs 684 per capita (NHSRC 2016), public health spending in China (2.9% of the GDP) and Brazil (4.1%). These insufficient changes over 10 years indicate that despite the NRHM, the impoverishment faced by the people as a result of catastrophic health costs is very likely continuing. The inadequate budgetary allocations described above are distributed very unevenly among different population categories, as the NHA 2013–2014 (NHSRC 2016, page 16) indicates.

the National Rural Health Mission (NRHM) policy framework embedded within itself space for private insurance, public private partnerships, etc. even as the document spoke of health as a right (Government of India 2016; Ministry of Health and Family Welfare 2017). The unregulated private sector is ripe with medical malpractices, irrational practice of medicines, exploitation of patients and medical misconduct (Gadre and Shukla 2016; Sivanandan 2016). The unethical practices in clinical trials, violations in reproductive health rights such as coercive sterilisations of women and the corruption involved in medical education with the connivance of the Medical Council of India do illustrate the same with substantial evidence (Parliament of India – Rajya Sabha 2012, 2016). The violations and character of the healthcare system reflect the caste-class-patriarchal biases that typify the denial of healthcare of the vulnerable populations en masse (Baru et al. 2010; Qadeer 2011a).

The result of the aforesaid scenario is palpable in the overall rising preventable morbidity and mortality and reported cases of abuse including medical negligence. These are violations of citizens' rights at the individual and systemic level. For example, communicable diseases contribute 28% of the entire disease burden (GOI 2017). Among these, more than 3.5 million Indians are affected by Tuberculosis and malaria which are often described as the diseases of the poor.[9] Deaths of infant and children under 5 years and maternal mortality, at a disproportionately high levels, along with an unequal distribution of mortality and morbidity allude to grievous systemic violations. Such violations converted to absolute numbers is only a symptom of the greater malaise that has affected the public health rights of citizens in India.[10]

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[9] Around 2.5 million people are estimated to be living with TB within India, about one-quarter of the global burden of TB (GOI 2017a). TB is one of the leading causes of death in India today with close to 5 lakh people dying in 1 year and 28 lakh cases detected in 2015 alone. India also has the highest burden of malaria among the Southeast Asian countries: data from 2014 indicates there were 1.1 million cases and 562 deaths due to malaria; however, in the last 10 years, total malaria cases have declined by 42% (GOI 2016).

[10] Approximately 12.5 lakh children under 5 years die every year whom an unfortunate 10 lakh die even before their first birthday. Estimates of maternal mortality ratio (MMR) are now at 167 deaths per 100,000 live births which translates to around 45,000 maternal deaths each year (Parliament of India 2016, para 2.40) (NFHS-4, IIPS 2017). The deaths of women and children are not evenly distributed across all states or all social groups, as studies have indicated. A child born to a scheduled tribe family has a 45% greater risk of dying in infancy compared to other social groups, especially if the ST family is in a rural area. Such differentials are seen within and between states. Maternal deaths among poorest women are reducing far more slowly than richer women who have better access to emergency obstetric care. The data from NFHS-3 (IIPS 2007) indicated that there are significant differences among women from the lowest and highest wealth quintiles in access to basic maternal services such as comprehensive ante-natal care or skilled attendance at childbirth.

One-fourth of rural women are underweight (with a BMI of less than 18.5 kg/m) although the national average has reduced from 36% to 23%, the proportion of women with anaemia has remained static, going from 55% to 53% in 10 years, and even now, half the pregnant women in the country are still anaemic. Comprehensive pregnancy care remains abysmal at 21% (NFHS-4 India Factsheet, IIPS 2017). This poor nutritional status of women in the reproductive age, coupled with their early marriages and lack of contraception, creates a significant probability of high-risk pregnancies in India.

Hence to gauge the impact and realisation of SRHC for accentuating citizenship through social citizenship, the existence of a public healthcare system supported by a pro-citizen, pro-people public policy is important. Provisioning for rights including right to healthcare and provisioning healthcare are two distinct features and are impacted by political, social and economic context even beyond the formal laws and constitutional articulations. Flood and Gross (2016:6) illustrate that 'two systems with similar rights provisions but different social/political systems... show dramatic differences in the realization of health rights'.

As seen in Fig. 2.1, medical profession is integral to the realisation of SRHC. In India, the ethical and moral decline of the medical profession looms large (Shukla and Gadre 2016). It's nexus with profiteering and private industries such as pharmaceuticals and diagnostics and failure to regulate the profession in the pretext of self-regulation has been widely debated in India (Baru and Diwate, 2015; Das et al. 2004; Parliament of India – Rajya Sabha 2012, 2016). The medical profession is a significant actor both in the violations of patients' rights and a barrier to the realisation of SRHC.

In the context of dual crises – both of the decline of public healthcare and lack of constitutional protection – civil society has attempted to use the judicial powers to elicit constitutional articulations and legal interpretations, which seem to have a limited impact on the public healthcare system. In such and other continued efforts, citizens have seen a ray of hope and have invoked ethics as the foothold to advocate for public health rights.

Rights and Ethics Interface: Foregrounding Ethics for Public Health Rights and Social Right to Healthcare

Marshall (1950) proposed social citizenship as an integral element of multidimensional citizenship. Even after seven decades after this theory was propounded, the idea of social citizenship has not received as much consideration as it requires. The crisis of public health and healthcare in India and constitutional ambiguities in protecting the social right to healthcare of the marginalised in India compel the ethical foregrounding to fortify citizenship. Social citizenship and the participation of citizens in the democratic, economic and civil life through SRHC would imply framing ethical arguments for a robust public healthcare system. Resisting the commodification of health has an overriding importance (Flood and Gross 2016:452). Such a process is however a contested arena and fraught with dilemmas and conflicts. In the following section, this is elaborated.

Contestations, Dilemmas and Conflicts

Social rights in general and in health and healthcare took a while to emerge out of the shadow of the politics that historically contested and constricted the discourse on human rights. The civil-political rights vs. social rights divide of the Cold War era is also summarised as the libertarian vs. egalitarian divide, and this has a special bearing on the SRHC discourse.

The civil-political rights are considered first-generation rights, and the social rights are considered second-generation rights. Both these enjoy a different status in countries in addressing the violations arising from any of these. The dichotomy between the understanding of human rights as indivisible-interdependent-universal, and the divide between the civil-political rights and social rights[11] in terms of justiciability, has received far greater acknowledgement in the recent years (Coomans and Maastricht 2006). There have been efforts to reinforce the unity of human rights as illustrated in the *Final Declaration of the Vienna World Conference on Human Rights* in 1993 which emphasised that 'all human rights are universal, indivisible, interdependent and interrelated' (UNOHCHR 1993).

Roemer (1989) traces this fragmentation to the twofold approach in human rights, i.e. libertarian and egalitarian, and traces its extension even in the discourse on SRHC. The former, in general, stresses on choice of the individual for medical treatment, while the latter focuses on access to healthcare of all citizens and distribution of healthcare services. Another debate on health rights revolves around the scope of rights, viz. right to health and right to healthcare. The underlying social determinants are said to be the root cause of illness, and they relate to inequity and structural inequalities and require adequate attention for the realisation of a meaningful right health (Chapman 2010). The right to healthcare on the other hand focuses on institutional arrangements, primarily for curative services.

Right to health and healthcare (as belonging to the domain of social rights) carries this historical tension and legacy of this divide with inherent difficulties of justiciability, enforcement and enjoyment of rights to health and healthcare. This divide has resonance in the Indian constitution as civil-political rights are considered justiciable fundamental rights and the social rights which include SRHC is in the domain of the DPSP, which is nonjusticiable. The implications of such a divide can be gauged by the fact that social rights in general including healthcare have taken longer duration to gain currency in the academic and policy discourses and remained incohesive up to the early 1990s.

The late twentieth- and early twenty-first-century crises of social rights have brought into focus the nature of citizenship and its various dimensions again. The notion of welfare State, which is at the core of the social relationship as explained by T. H. Marshal, has been shaken up due to overemphasis on market, the deterioration of the autonomy of the nation-State and the rise of the non-State actors. Social

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[11] In this paper, social rights is used for the sake of brevity to include and a mean by the expression of the broader rights under social, economic and cultural rights.

citizenship and SRHC face risks and restrictions on two counts. Firstly, political theories of Marshal and others are located within the framework of welfare State, and such a State is characterised as a ‘paternalistic State’. However, as the character of the State changes, healthcare along with public health also suffers irreversible blows as is experienced in the current economic policies and the neoliberal politics that legitimises it. Secondly, irrespective of the nature of the State, citizens and medical profession are placed in an imbalanced power relationship. Both these need protection and balancing for the realisation of a fuller social citizenship. In globalised economy, the global economic forces place constraint on the domestic economies of various countries, and economic rights supersede social rights. By contract, healthcare as a public good could be very well related to the antithesis social rights pose to market forces and market logic. ‘Social rights in their modern form imply an invasion of contract by status, the subordination of market price to social justice, the replacement of the free bargain by the declaration of rights’ (Marshal and Bottomore 1992:38).

These two contesting paradigms reshaping the SRHC discourses marked the end of the second millennium and the beginning of the third millennium. The dominant paradigm positioned health system being ‘an instrument of maintaining the hegemony of the dominant social order’, and the alternative paradigm foregrounded the possibility of being ‘an arena for asserting people’s claims for services and accountability, and hence people’s power’ (Shukla 2005). The latter view strongly endorses SRHC as a fundamental human right and proposes a militant discourse and approach to reclaim the public healthcare system. The right to health discourse also embodies the language of ‘struggle for health and right to healthcare’. Paul Farmer summarises this contention succinctly:

> We thus find ourselves at crossroads: health care can be considered a commodity to be sold, or it can be considered a basic social right. It cannot comfortably be considered both of these at the same time. This, I believe is the great drama of medicine at the start of this century. And this is the choice before all people of faith and good will in these dangerous times. (Farmer 2003:175)

McGregor (2001) argues that the neoliberal policies marked by individualism, free market via privatisation and deregulation have influenced the shaping of a healthcare system which commoditises healthcare as a market good. He makes the case for the need of an alternative approach that could bring dignity and a human face to healthcare to broaden the understanding of healthcare and challenging the neoliberal mindset. It is accepted that healthcare systems were one of the most affected social security systems severely affecting SRHC. The weight of structural adjustment programmes (SAP) was heavily imposed on cutting health spending and imposition of user fees coupled with healthcare reforms which primarily emphasised privatisation of healthcare services fundamentally turning healthcare as a purchasable commodity. Enforced by a new economic world order, ill-health is said to further aggravate poverty and marginalisation (Kim 2000).

The import of the above-mentioned divide can be gauged in the barriers that citizens and aggrieved patients feel in seeking justice in healthcare. Analysts have taken an institutional perspective to reposition SRHC as the outcome and interplay of a triangular relationship between the State, healthcare providers and citizens. This approach, arguably, goes beyond considering SRHC merely as goods and services onto focusing on institutional rules that govern the production and distribution of the social goods such as healthcare (Gauri and Brinks 2008:13).

The substantive justice is navigated through the instrumentality of procedural justice. The analysis in this research denotes to several dimensions of the procedural justice in health. In the following section, a critical appraisal is undertaken of the mechanism of procedural justice whose intended outcome is SRHC or social citizenship.

Violations of ethics protocols impacting the wellbeing and dignity of citizens occur in the web of these complex relationships. As SRHC is not a legal protected social right in India, challenging these power relationships happen on ethical-moral grounds rather than legal grounds. As much of this undefined and is left to the chaos of market forces, public health ethics vision potentially can provide the ethical protocols for the transformation of services into public health rights accentuating social citizenship in India.

Expanding the Horizons of Thinking Public Health Ethics

The constitutionalisation of right to healthcare as a fundamental right and consequently making provisions for healthcare and its various components through State or under the stewardship of the State provide a much needed impetus to argue for healthcare as a fundamental right (Biehl et al. 2016).

The repercussions of such a process are seen in realignment of the politics of the State with the market, largely observed as the decline or dismantling of the welfare State. It is noted that such developments signify not merely the influence of free market over the State, but rather that ‘the State has realigned itself in relation to capital (and in particular corporate capital) in such a way as to demonstrate that the State and the market are not in competition’ (Veitch et al. 2012: 262). Marketisation of public goods and services, as indicated in the marked shift of healthcare from being considered a public good to a private good, is signifier of the increased marketisation of social life in areas which were hitherto considered public in the framework of a welfare State. Such processes in healthcare are exemplified by private-public partnerships, increased commercialisation in healthcare services and promotion of unbridled corporate-business ventures in several related spheres such as medical tourism, clinical trials, surrogacy and tertiary-specialty healthcare. Regulatory measures are seldom driven by public welfare concern, and when reluctantly undertaken by the State – quite often as a response to public outcry in the face of grave violations of health rights – are marked by compromises that protect private commercial interests. In the contemporary period, State primarily pursues laws and regulatory policies not as public welfare entitlements, but rather, as part of a complex web of private or ‘public-private’ economic relations.

Conclusion

Rights, either can be founded on constitutional or legal frameworks or can emerge from long-term patterns of public policy, whereby rights, though not formally articulated, are acknowledged and exist as de facto rights (Flood and Gross 2016). Countries where SRHC is enjoyed the most are the ones which have a robust public healthcare system based on a strong and long-term public health policy and without explicit reference to health rights (Flood and Gross 2016:5). However, in countries such as India, where neither a robust public healthcare system exists nor a constitutional protection to public health rights, there is growing evidence for the increasing violations of citizens' wellbeing and dignity.

In the context of the Indian health scenario as discussed in this chapter, ethics and moral framework could be effective in consolidating access to affordable and quality healthcare. The domain of public healthcare is thronged with forces of competing interests and contestations. In such circumstances, the role of ethics entails creating political spaces for these debates and discourses, and in turn, influence various institutions and policies to redefine these relationships. Such discourses can address an array of issues including revision of policies that are violative of citizen rights and implementation of programmes and devise mechanisms for accountability for safeguarding SRHC. In the face of hostility, at best, it can attempt to make such violations visible to the civil society and public health community around.

In a democracy, distributive justice links public health in general and healthcare in particular to justice and rights (Edgren 1995; Qadeer and CSD 2015). Ethics perspective in public healthcare identifies imbalance of power and the need to stress on the less powerful and marginalised citizen's personhood as a central theme. Beyond the legal ambit, a strong ethics framework in public healthcare would be able to consolidate the SRHC and public health rights of citizens. The emerging public health ethics need to strongly foreground public health rights as an integral element of such a discourse.

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Part II

Ethics in Program Design, Implementation, Evaluation

Chapter 3
Knowledge, Framing, and Ethics in Programme Design and Evaluation

Suraj Jacob

Abstract This chapter will explore ethical issues surrounding the design and evaluation of public health programmes. For programme design, the chapter will argue that programme choice often occurs with solutions already in mind and that these solutions reflect "off-the-shelf" thinking (for instance, ubiquitous "training workshops"), implying little real "choice" in programme design. Further, at a broader level, programme choice is influenced by implicit ideological and epistemological positions that may be ethically dubious especially if they are not problematised and made transparent. On programme evaluation, the chapter focuses on ethical aspects of three key elements: participatory evaluation, the use of evaluation results and the place of impact evaluation. The chapter concludes with a discussion of the role of ethics in relation to epistemology. While it may be relatively uncontroversial to note the problematic ethics of research that comes up short when benchmarked against its own research / methodological paradigm, it is worth asking to what extent the choice of research / methodological / epistemological paradigm is itself an ethical one.

After independence, health policymaking in India gravitated to controlling infectious diseases and family planning through a techno-managerial approach rather than focusing on the primary health system (Amrith 2007).[1] From the 1990s, public health budgets were cut, private sector players encouraged, and a programmatic, verticalised approach to disease control became a feature of government policy. Rao (2017:21) notes: "Complex health problems were simplified into single-line technical solutions – DOTS [Directly Observed Treatment, Short Course] for TB (Tuberculosis), immunization for infant mortality, early diagnosis and

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[1] This went against earlier attempts at an inclusive model emphasising community engagement and environmental hygiene for positive health and wellbeing (for instance, see the ideas of the Bhore Committee). There were also occasional (but failed) attempts at an integrated approach later on, for instance, the National Health Policy of 1983.

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distribution of chloroquine tablets for malaria, and cataract surgeries for blindness". Although many of these programmes were integrated into a broader platform from 2005 (National Rural Health Mission, later National Health Mission), health *yojanas* (programmes) continue to be an important feature of policy. They target a variety of matters, such as institutionalised delivery (e.g. Janani Suraksha Yojana), health insurance (e.g. Rashtriya Swasthya Bima Yojana or Yeshasvini), adolescent health (Rashtriya Kishor Swasthya Karyakram), and so on.

In the backdrop of the importance of programmes in healthcare and health policy in India, this chapter explores ethical issues surrounding the design and evaluation of such programmes. In this chapter, a "programme" is taken to be an organised effort to address a public health need. Programme "design" refers broadly to how a public health approach is chosen and a programme constructed and justified with its expected processes and impact specified.

The chapter highlights a common tendency to design programmes without seriously problematising programme choice and assumptions, and it illustrates this through a case study (Sect. "Programme choice and design"). Programme "evaluation" refers broadly to the systematic investigation of the roll-out, processes and impact of a programme. The chapter highlights participatory approaches to evaluation (Sect. "Participatory and group-sensitive evaluation"), problematises the emphasis on impact evaluation in most mainstream evaluations (Sect. "The place of impact evaluation"), and explores what becomes of evaluation results (Sect. "Use of evaluation results"). The presentation reveals that discussions of ethical issues in public health programme design and evaluation inevitably confront the fundamental question of knowledge construction and power, and the chapter concludes with some thoughts on ethics and epistemology (Sect. "Conclusion").

Programme Choice and Design

"Off-the-Shelf" Programmes

How do policymakers choose and construct programmes? A careful approach would start with a wide-ranging and genuine "needs assessment" to identify the nature of the need/problem and the context within which it is located. A given need/problem can be potentially addressed in a variety of programmatic ways. Nevertheless, in reality, programme choice often occurs with solutions already in mind. Such solutions inevitably reflect "off-the-shelf" thinking rather than "out-of-the-box" thinking – for instance, ubiquitous "training workshops" are a ready solution – implying little real choice in programme design.[2] As Watkins et al. (2012:17) note, in designing programmes often "needs" are conflated with solutions in terms of inputs and activities, such as in the following statements: "What we really *need*

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[2] Further, where needs assessment is attempted, it is often reduced to a cursory "baseline survey" generating descriptive statistics rather than deeper probing of the situation to construct an understanding of the "how" and the "why" of the need/problem.

is to hire more staff members", "I *need* more resources", "They *need* more training". Rossi, et al. (2004:156) note:

> The human service professions operate with repertoires of established modes and types of intervention associated with their respective specialty areas. As a result, program design is often principally a matter of configuring a variation of familiar "off the shelf" services into a package that seems appropriate for a social problem without a close analysis of the match between those services and the nature of the problem.

A careful approach would brainstorm with intended programme beneficiaries, programme personnel, and others regarding different alternative solutions and their corresponding requirements and implications. Consider, for instance, the policy reaction to the tragic 2012 rape incident in Delhi ("Nirbhaya") that set off a large storm of protest. An immediate programmatic response by the government was to try to establish "women police stations".[3] While this may or may not be an appropriate response, it is not clear that needs were carefully articulated or alternative solutions gauged. Ubiquitous public service messages are another example of off-the-shelf thinking. In the context of family planning programme, Joseph (2004) writes:

> The Post & Telegraph Department made marriage greetings in attractive envelopes that curtly said, "For happy married life please be in touch with the Family Welfare Centre". In the late '60s the government pleaded, "Two or Three Children...Then Stop". When the fertile '60s ended, the campaign cancelled the kind option of the third child. "We Two Ours Two, Horn Ok Please," the highway trucks began to say. But all that came to nothing.

The argument here is not that it was wrong to have such exhortative messages. Rather, it is that the approach followed likely did not weigh alternative solutions in a participatory manner, going instead for off-the-shelf solutions that probably had limited impact.[4] The question then is: why are programme choices and assumptions not questioned more often? Part of it may be due to a disconnect between planners and programme designers on the one hand and programme managers and implementers on the other, and part of it may be due to a status quoist tendency (Kaplan and Garrett 2005). Further, at a broader level, programme choice is influenced by implicit ideological and epistemological positions that may be ethically dubious especially if they are not problematised and made transparent. The subsection below illustrates this in the context of a specific programme.

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[3] "All Delhi police stations to have women officers: Shinde", *Times of India*, December 29, 2012; "Only 442 women police stations across India: Police research data", *The Hindu*, December 25, 2012.

[4] More recently, the Health Ministry launched a "high-octane campaign with a three-in-one message of family planning, child spacing, and safe sex practices" ("What's the family plan", *The Hindu*, April 17, 2016).

Case Study: Tamil Nadu Integrated Nutrition Project (TINP)

The Tamil Nadu Integrated Nutrition Project (TINP) emphasised nutrition education, growth monitoring, and supplementary nutrition for pregnant and lactating mothers as well as infants. It ran as a large-scale intervention (in about 20,000 villages) in Tamil Nadu state over a long period (phase I in the 1980s, phase II in much of the 1990s, and phase III merging with the Integrated Child Development Service programme from the late 1990s). The World Bank considered the programme impactful/successful (World Bank 1994) and designed a similar programme in Bangladesh, the Bangladesh Integrated Nutrition Project (BINP) (Cartwright and Hardie 2012; White and Masset 2007).

Consider the logic (and implicit ethics) of programme choice in TINP. The programme was put in place after extensive studies and needs assessments as well as discussions of the state government with the World Bank. Heaver (2002:7) notes:

> TINP I was designed following a 1970s analysis, the Tamil Nadu Nutrition Study, which was probably the most elaborate nutrition study undertaken in the developing world by that time. In addition to carrying out anthropometry, it studied the consumption aspects of nutrition, food production and processing, and the relationship between income and employment growth and nutrition in the state. The study's broad scope led to wide-ranging nutrition strategy discussions between the state government and the Bank, and in turn to the initial identification of a complex, multi-sectoral project with components for growth monitoring, behavioral change, food supplementation, health care, food production, and food processing. In the course of a 16-month dialogue during project preparation, this initial broad menu of activities was reduced to the more limited TINP focus on growth promotion and improvement of maternal and child health services.

TINP was designed keeping in mind results from previous studies of nutrition in Tamil Nadu. Specifically, the focus on child nutrition came from studies of the strong relationship between child mortality and child nutrition. The focus on pregnant and lactating women and pre-school children also came from previous studies. The focus on nutrition education for mothers and growth monitoring of infants came from studies showing that child malnutrition occurred in many families with income levels that could ensure adequate diet. And the focus on supplementary feeding (i.e. only for children below a specified growth threshold and only until they crossed that threshold) was to help reduce dependency on the programme as well as to sharpen focus.[5] Targeting specific women and children, as well as emphasising supplementary rather than regular feeding, also helped with managerial and financial viability.

Based on fieldwork exploring how TINP played out in four caste communities, Sridhar (2008, 2010) provides empirical evidence to question assumptions partly based on which the programme was designed – for instance, that specific behavioural

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[5] That the programme was designed explicitly for supplementary rather than regular feeding cannot seriously be considered an ethical problem – feeding was not designed to directly redress diet or calorie problems and with carefully justified reasons. Further, in practice, programme personnel did not withhold food from children who expressed hunger even when they did not qualify based on the threshold (Sridhar 2008).

practices related to breast-feeding, washing, and balanced diet were obstacles to better nutrition and health and that behavioural change could occur through appropriate counselling and education. Sridhar (2010:128) points out instances not of ignorance and inappropriate or even uncaring practices but rather of structural limitations created by poverty and the labour market: "a tribal woman was told that she should breastfeed her child. However, she noted that she was unable to comply with this advice during the day because she was a daily labourer". Further, structural limitations were not just external to the household. Sridhar reports that in a majority of instances, women did not have control over household expenditure. Although many respondents knew about the importance of protein, vegetables, and a balanced diet, there was a substantial problem of diversion of household income by males for alcohol consumption. Overall, Sridhar (2010:130–1) notes:

> … women thus have knowledge about childcare, yet are constrained by lack of control over income and time. Women often mentioned lack of time, money, or control over household expenditure to explain why their child was not healthy. For example, when a woman stopped breastfeeding before the World Health Organization's recommended twelve months period, it was usually because she had limited time, insufficient milk, or because she was sick. Many of the low caste and tribal women had to work in the fields all day and upon returning felt that since they had been separated for more than eight hours from their child, their breasts were engorged and the milk had become sour. Instead of asking the health workers for more formula, out of fear of being chided, mothers would hide the fact that they were not breastfeeding. As a result, they would end up giving the baby sugar water, or cow or water buffalo milk. (van Hollen 2003)

From the perspective of ethics, what are we to make of this structural critique? Despite the exemplary due diligence displayed by programme designers in crafting programme components in response to what was known and understood about malnutrition in Tamil Nadu, given the training and inclinations of the economists and public health experts at the World Bank and in the Tamil Nadu government, the fact is that programme designers were operating with particular biomedical and health economics models. Sridhar (2010:123) argues:

> Within the Bank, the discipline of economics is hegemonic... an economic approach reduces problems, such as nutrition, to their core elements so that the professional expertise can digest them and prescribe solutions. … So the Bank framed nutrition using biomedical and economic inputs because it ultimately had to construct a problem that its own instruments could address. The Bank is in the lending business. It makes time-bound, repayable loans. Any Bank actions have to fit within the overall Bank goal of lending for growth.

The economic-biomedical approach did not sufficiently acknowledge the socio-economic positionality and structural disadvantage of the women and children that TINP was designed to address. In fact, a nonstructural approach implicitly creates a "framework of blame" where "a mother is admonished by health workers who simply assume that an undernourished child is the result of a mother's inadequacy" (Sridhar 2010:131). If this happens, it is inherently contradictory and ironic from an ethical perspective since a programme intended to improve the wellbeing of women and children may actually end up reducing the wellbeing of some.

Programme Evaluation

For programme evaluation, the chapter explores three aspects: participatory evaluation, the place of impact evaluation and the use of evaluation results.

Participatory and Group-Sensitive Evaluation

One principle of humanistic research and development practice, which extends to evaluation, is that of genuine, democratic engagement with individuals and groups encompassed by the research/evaluation. This extends both to data collection and to analysis – for instance, the participatory techniques spearheaded by Robert Chambers and associates (Chambers 2007) – as well as adopting an equity-sensitive lens to explore impact processes and outcomes associated with an intervention. Crishna (2006) notes four dimensions of participatory evaluation: those involved in the programme have some control over evaluation processes, evaluation objectives are jointly set by them, difficulties faced within this group are addressed as part of the evaluation, and the process is collectively empowering.

There is an insightful literature on community-based health planning, monitoring, and evaluation in India (for instance, Khanna 2013; Shukla et al. 2014). Chouinard (2013:238) distinguishes the sensibility of technocratic and participatory approaches:

> Evaluation, as it is envisioned in the current governance context, is intended to serve primarily an instrumental role… as a way to legitimize government activities, ensure cost-effectiveness, and enhance managerial decision making… The contrast between approaches that are more sensitive and responsive to community needs, such as participatory or collaborative approaches to evaluation, and accountability-driven technocratic approaches, is stark… [The mainstream, technocratic] approach to evaluation may well fall short of capturing the range of local views, contextualized meanings, and culturally relevant perspectives that are increasingly relevant today, and that participatory and collaborative approaches to evaluations are intended to capture.

Besides sensibility, such approaches are more explicit about seeing intervention processes and outcomes from a perspective of justice (Khanna 2013). For instance, equity-focused evaluation focuses on “assessments of what works and what does not work to reduce inequity” with an emphasis on “difficult-to-reach socially marginalized groups” (UNICEF 2011:9). Gender-sensitive evaluation is a particularly important aspect, especially in a development context where gender-related catch phrases have become the norm.[6] Emphasising specifics such as women’s control over their own bodies, political and legal spaces, private and public

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[6] Govinda (2012) notes several: “analysing gender inequality”, “promoting gender equity”, “mainstreaming gender”, “engendering development”, and “gender sensitisation”.

resources, and labour and income, gender-sensitive evaluation highlights the processes and extent to which an intervention changes and transforms gender relations (Chigateri and Saha 2016). UN Women (2015) notes:

> Gender-responsive evaluation has two essential elements: what the evaluation examines and how it is undertaken. It assesses the degree to which gender and power relationships—including structural and other causes that give rise to inequities, discrimination and unfair power relations, change as a result of an intervention using a process that is inclusive, participatory and respectful of all stakeholders (rights holders and duty bearers).

Besides gender, and more generally, evaluation has sought to take perspectives related to human rights (Kemp and Vanclay 2013), social impact (Esteves et al. 2012) and environmental impact (Morgan 2012). In the Indian context, besides class and gender, analyses based on social groups structured by caste, tribe and religion are particularly important from an equity perspective.

The Place of Impact Evaluation

Programme evaluation is about understanding how a programme unfolds (including in comparison with original expectations based on planning and the theory of change), why it unfolds as it does, and with what consequences (intended and unintended). The latter component – namely, consequences of programme roll-out or "impact evaluation" – has gained increased importance in recent times relative to other components such as "process evaluation". Since it is about an intervention and its consequences, impact evaluation has attracted the attention of those working on causal methodology in positivist social science. This literature has produced interesting methodological innovations centred around the logic of a "treatment group" and its counterfactual ("control group") where difference across otherwise "equivalent groups" is interpreted as the causal impact of the intervention (Cook and Campbell 1979; Dunning 2012; Duflo et al. 2007).

Not only is evaluation increasingly focused on impact evaluation, but impact evaluation is itself increasingly focused on the experimental RCT (randomised controlled trial or clinical trial) model, to which I turn below.

Equipoise and the Randomised Controlled Trial

An important ethical challenge of RCTs is that a potentially beneficial intervention is given to one group of individuals and deliberately denied to another group.[7] And the ethical justification is that RCTs can potentially generate new knowledge that can be used for future decision-making regarding programmes and policies that can improve wellbeing. That is, a necessary condition to ethically justify an RCT is that

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[7] Here, I am not taking up the more obvious ethical issue of doing harm, even unintentionally, as in the famous Stanford prison experiment (Zimbardo 1973).

it should reduce uncertainty about whether and how much a programme is impactful; this is referred to as "equipoise" (Freedman 1987).[8]

There are prominent studies in which the equipoise principle was violated, for instance, the Tuskegee Study of Untreated Syphilis (1932–1972) in which poor African-American men with untreated syphilis were followed even after the effectiveness of penicillin was established and it became widely available (Caplan 2001).[9] In such situations, sometimes a counterfactual ethical justification/argument is made: if the study participants were unlikely to have received the known effective treatment (in this case, penicillin) in the absence of the study, then the study by itself is not compromised ethically. However, there are in fact well-known ethical protocols – importantly, the Helsinki Declaration originating in 1964 (Riis 2003) – that require implementation of the "established effective intervention" in control groups (CIOMS 2002, Guideline 11). Such protocols protect vulnerable populations and especially those in the developing world in today's globalised research context (Angell 1997).

There is a further ethical nuance to consider. Outside of clinical medicine per se, and more properly in the domain of public health and social policy, many RCTs are conducted primarily to understand the *extent* of impact rather than to gauge *whether* or not the corresponding intervention will have positive impact. For instance, in the case of an RCT involving a vaccination camp or provision of midday meals, the logic of equipoise and established effective intervention are not at work – unlike, say, with a potential curative drug. Rather, the vaccination camp or midday meal RCT seeks primarily to gauge the extent of impact (on health, nutrition, and other indicators) in specific socio-economic and geographical contexts long after the clinical or health "value" of such interventions has been established. For instance, Banerjee et al. (2010) frame their RCT on vaccination camps by noting explicitly

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[8] Freedman (1987:141) notes that equipoise is "a state of genuine uncertainty … regarding the comparative therapeutic merits of each arm in a trial". For him, "clinical equipoise" is when there is "genuine uncertainty" on the part of the "expert medical community – not necessarily on the part of the individual investigator –about the preferred treatment". However, this is not without its critics. For instance, Miller and Brody (2003: 20) critique equipoise for viewing "clinical trials through a therapeutic lens". Relatedly, Clayton (1982) distinguishes between an "individual ethic" (avoid harm, provide equal benefit to each individual) and a "collective ethic" (acquire new knowledge so that individuals may benefit in the future). In this rendering, RCTs can be justified ethically when the latter counters the former.

While equipoise is about uncertainty regarding knowledge, there is also the related matter of clinical trials with methodological failures that have ethical consequences. May (1975: 25) notes that "one of the most serious ethical problems in clinical research is that of placing subjects at risk of injury, discomfort, or inconvenience in experiments where there are too few subjects for valid results, too many subjects for the point to be established, or an improperly designed random or double-blind procedure".

[9] The study had other ethical violations as well, for instance, deliberate deception of participants. Subsequently, a larger literature and consensus have developed around ethical dos and don'ts regarding research on human subjects, and these have been institutionalised in specific research contexts (for instance, in Institutional Review Boards).

that “[i]mmunisation is a highly cost effective way of improving survival in children in developing countries” and that yet there is little consensus on the best (institutional or other) way for implementing it. In other words, equipoise is invoked, but it is “implementation equipoise” – to coin a related term – and not clinical equipoise.[10]

Unfortunately, the world of “what works” in policy implementation is sparse in settled, context-appropriate knowledge. For instance, in the case of vaccination, Banerjee et al. (2010) find that small material incentives may be more cost-effective than simply improving reliable supply. Yet we know little about what aspects of the specific context of the RCT (NGO intervention among poor tribal villagers of southern Rajasthan) may have contributed to the results and whether and how the results carry over to other contexts (nontribal villages even in the same region or peri-urban areas). Indeed, the absence of a sizeable literature on the context-specific nature of implementation (Konkipudi and Jacob 2017), and therefore also impact, provides a relatively strong case for implementation equipoise even though the literature does not articulate it in such terms. This holds in broader terms for all “pilot projects” where an intervention is tested out on some subset of a target population.

Humanistic Critique

RCTs and other interventions with an evaluative component (such as pilot projects) sometimes tend to have other characteristics that have attracted critiques. One critique relates to the ethics of experimentation that disproportionately falls on the marginalised, of which the Tuskegee study is an example. Reddy (2012: 68) points out:

> … the relative disorganisation of poor people and poor communities, which makes it possible to experiment upon them without facing much resistance… It would very likely be politically unpalatable to provide a recognisable benefit randomly to middle-class or upper-class individuals or communities, and, at a minimum, to do so would involve complex political negotiation.

A second critique is that evaluation-centric interventions tend to take a non-humanistic, engineering approach where intervenors stand in a privileged position outside the community/system in which the intervention occurs, as suggested by the TINP case study. Sridhar (2010:128) suggests that programme instructions to front-line workers took an economic-biomedical approach that did not encourage autonomy or empathy in programme personnel: “at the front line, the community workers did not have enough time to discuss caring practices with women… more emphasis [was] placed on producing written educational materials than on actually speaking to women about health and nutrition”.

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[10] However, this has come in for criticism. For instance, Glewwe et al. (2012) report an RCT gauging the extent to which students with eyesight problems do better at school if they wear corrective eyeglasses. For a critique from the perspective of clinical equipoise, see Ziliak and Teather-Posadas (2016).

Further, the overall approach of TINP may also have tended to view programme personnel, especially frontline workers, as cogs in the intervention-evaluation machinery. Sridhar (2010:127) notes: "The health workers routinely collected massive amounts of data, usually not fully understanding why they were doing it or what the information would be used for". Similarly, Mishra (2014:966) notes that frontline health workers in Odisha "ensured that all state health services were moulded to accommodate local aetiologies of illness and remedies… However, these efforts were confined to the community space and never shared with senior health officials, lest this might be seen as promoting quackery".

Impact Evaluation: Causation Without the "Why"

The discussion regarding ethical complexities with RCTs and the non-humanistic approach of evaluation-centric interventions more generally is not applicable to impact evaluation approaches that are not intervention-based. Such approaches, often called natural experiments or quasi-experiments, have ethical and logistical advantages over experimental/intervention-based approaches (Cook and Campbell 1979; Dunning 2012). Nevertheless, both intervention-based and quasi-experimental approaches can be critiqued for an epistemology that is ethically problematic, as discussed below.

In impact evaluation, impact is "the positive and negative, intended and unintended, direct and indirect, primary and secondary effects produced by an intervention" (definition from the OECD Development Assistance Committee; see Rogers 2012). Almost the entire focus on impact evaluation is to legitimately estimate the size/extent of impact that can be causally attributed to an intervention. Given this, experimental or quasi-experimental evaluation cannot explain how impact occurs. Addressing the "how" question would require understanding the processes and contexts within which interventions play out. Nevertheless, positivist methodologies of impact evaluation are framed explicitly around their ability to produce estimates of the causal impact of an intervention on an outcome. The irony is that these approaches claim to estimate empirical causal impact without actually empirically explaining why the impact is what it is estimated to be – in other words, causality which does not address the "why"!

Why is it important for evaluation to understand impact processes – how and why a particular impact obtains – rather than only estimate causal impact? Dalkin et al. (2015) note:

> …it is necessary to establish what goes on in the system that connects its various inputs and outputs… In pharmacology, the term 'mechanism of action' refers to the specific biochemical interaction through which a drug substance acts on the body to generate its curative effect. Programme evaluators do not suppose that CCTV (the intervention) causes a fall in crime rates (the outcome). It does so, when it does so, by persuading potential perpetrators of increased risks of detection (the mechanism). In all cases, science delves into the 'black box'.

Impact evaluation studies typically specify the theoretical mechanism(s) linking intervention and projected outcomes, but even if it is empirically established that the outcomes occurred as projected, it does not sufficiently establish the validity of the proposed theoretical mechanism as empirical causal explanation (Woodward 2017). Rather, what is needed is empirical tracing out of the process(es) through which the intervention in a particular context produced the outcomes causally attributed to it (Jacob et al. 2015). As Smith et al. (2002:72) note, we often intuitively assume processes without empirically establishing them:

> It makes intuitive sense that better working conditions would improve productivity. In the same way it is clear that street lighting or closed-circuit television (CCTV) should work by increasing surveillability. Plague reduction should work by drowning witches, and fever should be reduced by the extraction of overheated blood. We have been too ready to assume that how crime prevention *should* work is the way crime prevention *does* work.

Biomedical studies show the enormous variation in impact and point the way to the importance of understanding process and context. For instance, studies based on mice and meant to throw light on human physiology may not even be generalisable to all mice contexts since it turns out that the specific type of mouse used in laboratory experiments (Black 6) is “a teenaged, alcoholic couch potato with a weakened immune system, and he might be a little hard of hearing” (Engber 2011). In the case of TINP, based on its perceived success (George et al. 1993; World Bank 1994), the World Bank conceived and funded a similarly massive programme in Bangladesh. Nevertheless, BINP has been judged to be a failure even apart from implementation weaknesses (White and Masset 2007; World Bank 2005). Cartwright and Hardie (2012) note that an important contextual difference – and one that programme designers and implementers ignored because of their a-contextual approach to “scaling up” – was that in Tamil Nadu decisions on infant nutrition revolve around the mother, but in Bangladesh they revolve around the paternal grandmother. This implies that programmes such as BINP focused on changing the knowledge and behaviour of mothers are less likely to create large positive impact.

Writing about public health in India, Prashanth et al. (2013:36–37) note that the challenge is about “focusing on ‘how’ interventions to improve health services work in addition to understanding if they work”. They scrutinise all published evaluations of public health programmes in India over a 5-year period and note that few trace processes of impact and indeed only 34 of 93 even reported the context within which the intervention produced the outcomes that were being reported. They explicitly note a sad reality in the literature (Prashanth et al. 2013:44): “In spite of several health and related social initiatives taken up under the National Rural Health Mission (NRHM) and various national-level schemes in the country, the policy-relevant question what worked for whom and under what conditions remains largely unanswered”.

Although impact evaluation studies seldom undertake process tracing, in fact, the impact evaluation approach offers a potentially excellent starting point for doing so, namely the “heterogeneity effect”: estimated causal impact of an intervention is an average that may be distributed widely.[11] Deaton (2010:430) notes: "heterogeneity is not a technical problem calling for an econometric solution but a reflection of the fact that we have not started on our proper business, which is trying to understand what is going on". If the estimated average impact is relatively higher among some individuals or groups compared to others, it forms an excellent starting point to explore causal processes and contexts for explaining why this is so. Consider the impact evaluation study by Lim et al. (2010) of the Janani Suraksha Yojana (JSY), a conditional cash transfer scheme for promoting institutional delivery. The study uses a quasi-experimental methodology to establish that on average JSY reduced perinatal and neonatal mortality rate. However, it also finds considerable heterogeneity around this average based on region, socio-economic group, and so on. Prashanth et al. (2013:39) note:

> It concludes that conditional cash transfer schemes such as JSY, through incentivizing institutional delivery, could 'somehow' improve particular health outcomes. However, crucial information for policymakers and decision-makers at district and sub-district level is related to why there were differences among beneficiaries, and why within districts some women did not avail the scheme, or did not benefit from the scheme in spite of availing the scheme.

Local specifics of caste and class matter enormously for public health processes. Mishra (2014:968) notes that in one Odisha village, "villagers even refused to lead us to the ASHA's residence and later complained about how indifferent and inactive an ASHA she was. We learned that this ASHA's recruitment had been controversial, as she was married to a rich contractor and a converted Christian, pitting her as someone who is privileged and unfit to relate to the concerns of the villagers". More generally, Mishra (2014:961) notes:

> Existing literature on global programmatic experiences with integration of health services tend to approach delivery of services as a technical and mechanistic process … The focus on supply-side health system factors, though important, assumes that community demand relies unproblematically on providers delivering services…. Ethnographic evidence suggests that the demand/uptake of health services is linked to a host of factors, such as the community's perceived vulnerability to a specific illness for which the health service is offered, previous experiences with other state health services, modes of health communication, interaction with health workers and broader political identities and perceptions of the state by the community…

Woolcock (2013:230) critiques inconsistency in approach to rigour in the typical impact evaluation approach:

> … having expended enormous effort and resources in procuring a clean estimate of a project's impact, and having successfully defended the finding under vigorous questioning at professional seminars and review sessions, the standards for inferring that similar results can be expected elsewhere or when 'scaled up' suddenly drop away markedly. The 'rigorous result', if 'significantly positive', translates all too quickly into implicit or explicit claims

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[11] Interestingly, participatory and group-sensitive evaluation approaches naturally take process and context more in their stride than do conventional approaches: "Equity-focused evaluations pay particular attention to process and contextual analysis, while conventional impact evaluation designs use a pre-test/post-test comparison group design, which does not study the processes through which interventions are implemented nor the context in which they operate" (UNICEF 2011:9–10). See also Batliwala and Pittman (2010).

> that the intervention now has the status of a veritable ‘best practice’, the very ‘rigor’ of ‘the evidence’ invoked to promote or defend the project’s introduction into a novel (perhaps highly uncertain) context, wherein it is confidently assumed that it will also now ‘work’.

Finally, and quite apart from what impact evaluation cannot tell us – although implicitly insisting it does so – because of absence of empirical process tracing, impact evaluation approaches are also limited as they cannot tackle several important questions, viz. those not amenable to construction of relevant control groups. Reddy (2012:63) notes that “[t]hese include questions related to the structure and dynamics of markets, governmental institutions, macroeconomic policies, the workings of social classes, castes, and networks, and so forth”.

Use of Evaluation Results

Why is programme evaluation conducted? There are, of course, standard, legitimate answers to this question. Evaluation can help improve programme implementation in ongoing and later rounds, keep programme personnel accountable, decide whether a programme should be continued, and foster organisational learning (Alkin 2010). However, evaluation sometimes becomes merely “ritualistic” in nature (Rossi et al. 2004) – mandated by programme sponsors/donors and conducted desultorily, often to justify predetermined funding and policy choices and with little commitment to use evaluation findings meaningfully.[12] This turns the spotlight on the motivation of the evaluation sponsor and the purpose and credible uses of evaluation.[13]

In India, the Planning Commission took a proactive interest in programme evaluation in its early years and created an independent and technically competent agency (the Planning Evaluation Office, PEO) to evaluate plan programmes. Further, PEO reports were sent to Members of Parliament, and some public discussion occurred (Pal and Chakrabarti); they were also an important agenda item at the annual conference of State Development Commissioners (Mehrotra 2013). From the 1970s there was a decline in the importance of evaluation, partly due to decline in the role of the Planning Commission itself as an agent of development. In the late 1970s, the Dubhashi Committee on the PEO noted the low use of evaluation reports and highlighted both supply-side weaknesses (poor evaluation) as well as inadequate

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[12] In the context of ethics, it is also worth raising the question of who the evaluator should be answerable to. In practice, typically accountability is to evaluation sponsors and programme funders alone rather than to intended beneficiaries and specific marginalised groups, and this is particularly problematic where evaluation is merely “ritualistic”.

[13] Although in the text I do not discuss the problem of poor-quality evaluation reports, this is also an important reality in the Indian context, particularly when “[e]valuations are typically carried out by professionals who have neither an evaluation background nor a good understanding of how governments function”, so that evaluation reports merely “contain generalised statements” rather than contextually relevant recommendations based on real-world processes and pragmatic judgements (Kumar 2010:239).

institutional follow-up of evaluation reports. However, even in the more robust evaluation period earlier, there was little evaluation capacity available outside the Planning Commission, particularly in state governments, and evaluation was seen primarily from the perspective of intra-government accountability rather than social accountability (Pal and Chakrabarti). Notes Kumar (2010:239):

> Anything passes off for evaluation…. A tradition of evaluation is yet to permeate the administrative, bureaucratic, and political cultures of most South Asian countries. Most managers are fearful of evaluation; they see it as an audit or a fault-finding exercise.

With greater pluralisation in governance over time, particularly from the 1990s, civil society groups became more active in evaluation and accountability in India. There was also a turn towards donor-imposed evaluation frameworks, but this was "to evaluate against donor criteria for donor needs—and according to the criteria and methods the donor has preselected" (Carden 2010:220).[14]

Conclusion

Much of the discussion of ethics in this chapter was interwoven with issues of knowledge construction and framing. One aspect is the ethical implication of insufficient fealty to research methodology and presentation within the approach chosen by an evaluation. Unfortunately, this applies to a large number of public health evaluation studies from India. As Altman (1980:1183) notes, "it is unethical to publish results that are incorrect or misleading…. Once published, a piece of research achieves both respectability and credibility…" While it may be relatively uncontroversial to note the problematic ethics of research that comes up short when benchmarked against its own research/methodological paradigm, it is worth asking to what extent the choice of research / methodological / epistemological paradigm is itself an ethical one. Scientism – "the conviction that we can no longer understand science as one form of possible knowledge, but rather must identify knowledge with science" (Habermas 1971:4, cited in St. Pierre 2006) – can produce a closing off of alternative knowledges, which has ethical implications.

An ethic and ethics of *anekantavada* (multifacetedness of knowledge and truth) would imply a very different approach to public health programme design and evaluation. The routine application of off-the-shelf programme ideas would need to be rethought (and the shelf likely dismantled), as would the broader technocratic approaches that currently hold sway in programme design (as evidenced by the biomedical, health economics approach of TINP). In the field of evaluation, participatory co-production of knowledge would need to be emphasised, changes in

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[14] Of the three types of "evaluation orientation" distinguished by Carden and Alkin (2012) – use-oriented approaches, values-oriented approaches, and methods-oriented approaches – donor-driven evaluation focuses more on the third and is particularly weak on the second (for instance, genuinely participatory methodologies, as discussed earlier), whereas both the second and the first are likely of greater relevance for the programme beneficiaries and the programme itself.

social relations highlighted, the present emphasis on impact estimation broadened to an understanding of underlying processes and contexts and the evaluation results better integrated with broader policymaking.

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Chapter 4
Ethical Analysis of Public Health Programmes: What Does It Entail?

Giridhara R. Babu and A. Yamuna

Abstract While several professions have ethical guidelines set by their own professional bodies, such guidance is often not available for implementation of public health programmes. Therefore, very often, ethical perspectives involving the public health programmes (PHPs) are neglected. As a result, several ethical issues arise during the implementation phase. This chapter examines three key principles, namely, respect to persons, beneficence, and justice, and explores its applicability to public health practice. It analyse this framework using three case studies: the Revised National Tuberculosis Control Program (RNTCP), introduction of Human Papilloma Virus (HPV) vaccines in India, and polio eradication (PE) programme. We used the published literature, reports of ongoing national programmes, and documents outlining ethical principles published by national and international organizations to analyse the components of the framework. Each case study informs the multifaceted dimensions of ethical issues and challenges associated with a specific programme. In the absence of clearly developed guidance, we illustrate how using our proposed framework can identify and resolve ethical issues in the existing public health programmes.

Keywords Ethical analysis · Public health programmes · Respect for persons · Beneficence · Justice

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Background

Public health professionals face ethical dilemmas on innumerable occasions while implementing the public health programmes. Some of them include lack of resources for appropriate ethical management, difficult choices between addressing the lack of awareness and providing apt information to the people, negotiating political framework, privacy and confidentiality of the collected data, prevention and control of infectious diseases, addressing the health issues of the immigrant population, challenges due to the community norms vs individual choices, etc. In such instances, it is very difficult to distinguish prescriptive advice stemming from moral expectations and ethical standards. Baum classifies the challenges faced by public health professionals into five categories: defining the authority, decision-making related to resources, managing political influence, ensuring quality of care in programmes, and upholding importance and scope of public health (Baum et al. 2009). In addition, the implementers have to endure other indirect, nonetheless, tough ethical challenges including balancing population health benefits with cost-effectiveness, ensuring autonomy, prioritizing public health problems, distribution of funds, limited control over decision-making, political issues and pressure (Baum et al. 2009). Other challenges include inaccuracy in data assessment and reporting which is collected among different groups such as race, religion, location, socioeconomic status, etc.; dissemination of health information; and relationships with the legislative and regulatory arms of government (Bernheim 2003). Confronted with these issues, the choice of exercising ethically right or wrong decisions is often done by subjective interpretations. While several professions have ethical guidelines set by their own professional bodies, such guidance is often not available for implementation of public health programmes. Therefore, there is an urgent need for evaluating ethical frameworks for utilization in analysing public health problems.

Most of the public health programmes (e.g. immunization, mandatory screening for any infectious disease in airports) are implemented with utilitarian ethics, in the belief that the programme promotes the greatest health for the greatest number of people (State et al. 2004). In order to decide whether the public health programme is ethically right or wrong, a definitive, verifiable ethical guidelines should be available for measuring both beneficial and adverse ethical consequences as a result of the programme. However, rarely does such framework exist, in any public health programme, which mandates measuring and reporting the very objectives of the utilitarian goal. For example, public health programmes do not have data on analysing effectiveness; respecting human rights, cultural beliefs, and equity in implementation; respecting individual choice; or informing pros and cons of any given public health programme. The need for reducing conflict and uncertainty in public health decision-making is mostly seen as frivolous by the implementers. For the public health professionals, safeguarding the rights of individuals with respect to ethical principles is a real challenge and needs a broad understanding of ethical analysis. In order to reduce any conflict and uncertainty in public health decision-making, it is important that specific orientation, skill training, and knowledge of ethical guidelines are imparted to the implementers about benefits and harm of the public health programme. Availability of an ethical framework can help build the capacity of the implementers in efficient management of the ethical dilemmas arising in implementation of the programme (Roberts and Reich 2002).

Existing Ethical Frameworks for Public Health Practice

Kass (2001) proposed ethical framework of public health, which included six steps: need of identifying the public health goals, assessing effectiveness of the programme in achieving its stated goals, determining known or potential burdens of the programme, making alternative approaches to minimize or reduce the burden of the programme, executing the program with ethical principle of justice and fair distribution of benefits and burdens, and balancing between benefits and burdens of a programme (Kass 2001). Childress et al. (2002) suggested additional ethical framework in public health ethics which includes producing benefits, avoiding, preventing, and removing harms; producing the maximal balance of benefits over harms and other costs (often called utility); distributing benefits and burdens fairly (distributive justice); ensuring public participation, including the participation of affected parties (procedural justice); respecting autonomous choices and actions, including liberty of action; protecting privacy and confidentiality; keeping promises and commitments; disclosing information as well as speaking truthfully; and building and maintaining trust (Childress et al. 2002). Bernheim et al. developed a guide to solve the ethical issues in public health practice, and it includes list of questions subdivided in four main areas such as assessing public health practice, identifying and recognizing ethical issues and considerations, identifying options and making and implementing public health decisions, and evaluating the resolution(s) (Bernheim et al. 2007). Baum et al. (2007) suggested six steps of ethical framework, and these are as follows: determine population-level utility of the proposed action, demonstrate evidence of the need and effectiveness of actions, establish fairness of goals and proposed implementation strategies, demonstrate accountability, assess expected efficiencies and costs associated with the proposed action, and consider political feasibility and community acceptance (Baum et al. 2007). Further Bernheim et al. put forward three ethical frameworks such as analysing the ethical issues in context, evaluating the alternative approaches used in the context, and justifying the interventions (Bernheim et al. 2009).

We propose examining the framework comprising of the trinity principles of *respect for persons*, *beneficence*, and *justice* to guide ethical behaviour. This is an improved version of an earlier published paper and extension of evidence in this regard (Babu et al. 2014). The purpose of this chapter is to examine the framework of ethical principles often applied in the context of research – *respect to persons*, *beneficence*, and *justice* – and explore its applicability to public health practice. Specifically, our approach uses key ethical principles with applied framework to examine the ethical basis of certain public health programmes in India. The objective of the chapter is to stimulate the implementers to apply an ethical framework in the formulation and implementation of public health programmes.

Methods

For the purposes of this chapter, public health practice is defined as "any engagement of public health professionals for implementation of public health programs" (State et al. 2004). We studied the published literature, reports of ongoing national programmes, and documents outlining ethical principles published by international organizations (Dye et al. 2006, 2008; Eradication et al. 1993; Nelson–Rees 2001; Association 1964; Biomedical and 1979; Sciences 2002). For our review, we selected three examples from India in the area of current public health practice: (1) the Revised National Tuberculosis Control Program (RNTCP), (2) introduction of HPV vaccine in India, and (3) polio eradication (PE) programme. We used the following definitions in evaluating current public health programmes. Violation of any one of the principles in the framework was seen as a ethical as well as programmatic deficiency or weak point (Fig. 4.1, Source: Authors).

The term "respect for persons" (also referred to as autonomy) implies that the choices of autonomous individuals are respected, and individuals incapable of making their own choices are protected, and adequate information provision occurs to lead to informed decision-making (Association 1964; Biomedical and 1979; Sciences 2002). Respect for persons has also been used in the realm of the need to listen to and pay attention to the needs and expectations of communities.

The term *justice* in the context of public health programmes would imply that individuals and communities should not be exploited, selection for participation in programmes must be fair, and vulnerable individuals who may benefit will not

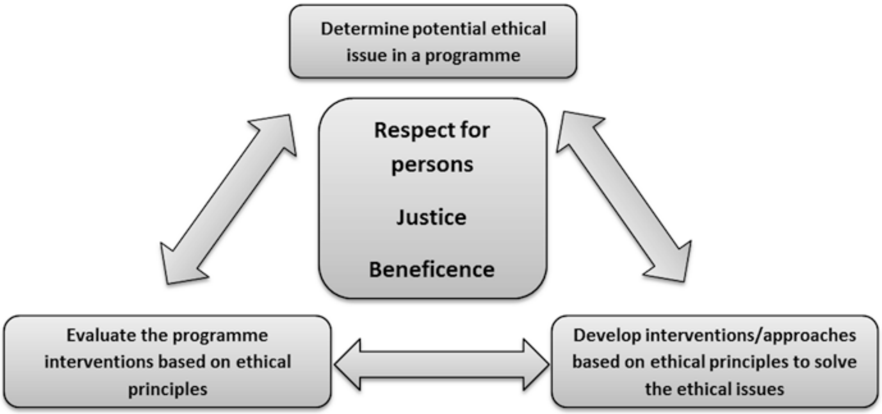


Fig. 4.1 Proposed ethical framework in public health programme

be excluded without good reason (Association 1964; Biomedical and 1979; Sciences 2002).

The term *beneficence* means that participation in any public health programme should be associated with a favourable risk-benefit ratio. It thus means that public health interventions maximize possible benefits while minimizing potential harm (Association 1964; Biomedical and 1979; Sciences 2002).

In the sections named by the ongoing public health programmes, we present the results of applying the proposed ethical framework.

Revised National Tuberculosis Control Program

The Revised National Tuberculosis Control Program (RNTCP) is the country's primary vertical programme to control tuberculosis (TB). All member states of the World Health Organization (WHO) adopted the goal of detecting at least 70% of all new infectious cases arising each year and to cure at least 85% of those detected by 2000 (later changed to 2015) (WHO 1991). The Millennium Development Goal (MDG) 6c of decreasing the incidence of TB can be approached in one of the two ways: (1) Define cases of TB to actually reflect the entire population who are at risk and determine detection rates based on such a definition. This entails improvements in detection and reporting, which are impossible without effecting improvements in public health surveillance and addressing challenges in human resources and infrastructure management to maximize reach in the community, (2) Continue with the same definition of incidence and conclude that TB is under control. The latter approach presents the risk of neglect of primary health infrastructure enhancement in favour of greater focus on a vertical programme (Table 4.1, Source: Authors' compilation from data available from Government of India 2017).

Simple and more practically oriented epidemiological tools can solve current problems of uncertainty in measurement of disease and its impact on the population and obviate a false sense of accomplishment (Babu 2008). It is recommended that

Table 4.1 Challenges in estimation of tuberculosis burden in India

Captured cases			Missed cases		
Type	Notation	Estimations	Type	Notation	Estimations
Diagnosed incident cases	**b**	1.3 million	Incident deaths	**a**	480,000–500,000[a] per year
Treated prevalent cases	**d**	1.3 million per year	Missed incident cases	**c**	3.3 million
Estimated prevalent cases	**p**	5 million	Dead prevalent cases	**E**	700000[a]
Total incident cases	**i**	2.3 million (2–2.5 million)	Undiagnosed in network	**F**	100,000 per year
			Undiagnosed outside network	**G**	1 million

[a] Assuming case fatality rate of 14%

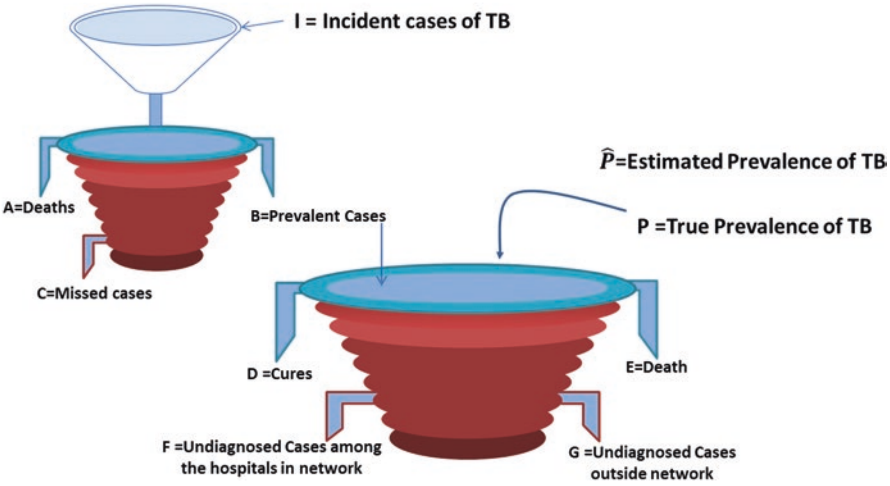


Fig. 4.2 Diagram describing estimations in tuberculosis burden

population measures of disease, such as incidence and prevalence, be better defined in TB programme implementation context and that clarity on which aspects of disease measures are being addressed be provided to all (Fig. 4.2) (Babu and Laxminarayan 2012). This shall address the issue of false declaration of reduction of TB cases.

Without drastically changing the terminologies used in the current programme, the estimated incidence in India is falling short by at least one million per year. As per TB India annual report 2017, the incidence of TB has reduced from 289/lakh/year to 217/lakh/year since 2000 to 2015, and the mortality due to TB has reduced from 56/lakh/year in 2000 to 36/lakh/year in 2015. For a period of 1 year, this would result in a backlog of one million patients outside the network, who may or not get treated. In addition, approximately 100,000 patients are not diagnosed as tuberculosis even within the network of RNTCP hospitals. That means they add up 500, 000 in the last 5 years. In effect, this means over one million people per year would be potentially transmitting the disease to the uninfected population, and the number keeps growing as the programme sees no correction (e.g. five million in the last 5 years). If we assume the case fatality rate at around 14% among the untreated cases, the proportion of incident deaths missed from the system would be 350,000 per year. These are simply the preventable deaths, only if we had a proper system in place to include them in coverage and only if we had a proper definition of incidence in the first place. Therefore, the core ethical challenge in the programme stems from the very definition of tuberculosis, used in the RNTC programme till now. The programme till now was geared towards the convenience of calculating an estimate and failed to effectively prioritize and address the goal of finding all the TB infections and ensuring provision of treatment.

Justice

Considering the *justice* perspective, focus on *prevention, early diagnosis and comprehensive case detection* was completely absent from this programme. As illustrated by the above analogy, the biggest ethical challenge is that millions of patients are not diagnosed due to the faulty premise of expecting them to visit health facilities. In a country where nearly 60% of the patients visit private facilities and most of these hospitals not registering to report the TB cases to the government despite making TB a mandatory disease which is to be reported to the government. From a justice perspective, missing millions of TB patients from the ambit of diagnosis and treatment is a colossal ethical disaster. Further technology, however developed it is, has not been able to provide a feasible point of care diagnostic test for tuberculosis. Therefore, the biggest ethical challenge is letting the false negatives keep spreading the disease under the belief that they do not have the disease. Not providing the correct diagnosis after doing so-called "diagnostic" test misses not only the opportunity of treating but further aggravates the disease and spread in a community. Also, it is completely unethical to term prevalence cases as incident cases thereby resulting in only a marginal reduction of TB cases and, therefore, shall result in falsely declaring that new burden of disease has fallen. Maintaining the autonomy of the vulnerable people is important while actively screening socially vulnerable group. Currently, there is no national- or state-level guidance to respect the autonomy of the vulnerable groups and, at the least, including slum dwellers, migrant workers, prisoners, vulnerable children, elderly, tribal and indigenous populations, miners, and notified economically backward districts. Using community resources like ASHA, "Panchayat" bodies, Self Help Groups (SHGs), and informal care providers, undertaking symptom screen in the community followed by sputum collection from symptomatic would be beneficial (Babu et al. 2014). Instead of directing the policy towards prevention and initiating the population screening for missed patients, the programme hitherto focused only on "patient-initiated pathway," focusing on TB case detection in health facilities as the first. Despite the recent policy of mandatory notification of TB in India (Bhaumik and Biswas, 2012), a significant number of care providers in a private sector are not part of the network. Also, many doctors (public/private) do not suspect TB when presented to them, do not report when they suspect, and are not aware of compliance if they start on treatment. Most of the problems with preventive efforts (including wider coverage and screening) can be resolved by increased allocation and importance provided to public health efforts (such as comprehensive screening and early diagnosis).

Beneficence

The ethical principle of *beneficence* is disrupted on several levels. As per the standard definitions in infectious epidemiology, the source population for the detection of tuberculosis (TB) should include all the persons who are at risk of acquiring tuberculosis infection. Consequently, incidence rates of TB should reflect new infections or new cases of active TB (Rothman et al. 2008). One, it treats new and old cases TB as the same (old but not detected, immune cases, infectious but not active TB) (Rothman et al. 2008). Two, detection rates will not reflect all the new cases, since not all patients with new infections or active TB have access to health facilities. Third, smear-negative status means that TB infections are absent; with an accuracy of nearly 50%, nearly half of the cases go undetected (Begum et al. 2007; Van Der Werf and Borgdorff 2007; Attaran 2005). Evidence suggests that 90% who suffer from TB are not given any scientific treatment and 87% of people diagnosed on the basis of X-ray alone are unlikely to have TB (Porter and Ogden 1997). Apart from addressing the determinants of health in the long run, these preventive efforts including educating the masses are outside the ambit of management by healthcare providers, and merely mandating them to report won’t change the current scenario. The TB detection rates in the country is tenuous as incidence rates, as it considers the number of new “smear-positive” patients detected each year as the numerator divided by the total number of examined smears. This is undoubtedly operationally convenient and practically feasible but fails in indicating the actual burden in the community (Chauhan and Agarwal 2005), an inaccurate estimation of TB incidence for many reasons. Although the programme documents mention that the goal of their programme was to decrease incidence, all the efforts were directed only on decreasing prevalence (diagnosed and existing cases) for decades. What would have ideally decreased the incidence were preventive measures such as research and introduction of an effective vaccine and addressing the determinants of health (housing to reduce overcrowding, etc.) in preference to therapeutic measures. Failure to effectively prioritize and address the goal of finding all TB infections in the community and providing treatment creates an ethical challenge, with “primary and primordial prevention” completely missed in the programme. All this confusion has surfaced by labelling prevalent cases as incident cases, thereby resulting in marginal reduction of TB cases. Therefore both the potentials of maximizing benefits and averting the population risk are neglected.

Respect for Persons

The ethical principle of *respect for persons* is violated because there is either partial or complete absence of critical information provided to a common man as well as to policymakers to base decisions on whether truly reducing incidence or treating largely prevalence of TB cases (Porter and Ogden 1997). For example, a person labelled as

Table 4.2 Ways to achieve universal access to TB treatment

Diagnose all persons with TB under RNTCP and DOTS treatment
Engaging community participation to provide universal access
Community involvement through village health and sanitation committee to spread awareness about TB and importance of reporting cases
Removing false beliefs about TB and provide awareness that TB is completely curable

negative, but not informed that the test is inconclusive; and therefore, person is unable to make an informed decision on the next course of action. There is a strong need of population screening, change the diagnostic algorithm to include molecular tests, as far as possible in a single patient visit, preventing drop out from diagnostic pathways, enabling different diagnostic algorithms in different health care settings depending on the availability of smear, X-ray and molecular tests and referral of patients and specimen to the sophisticated diagnostic centres.

Resolution of Ethical Problems

India has one fifth of the world's burden of tuberculosis (Dewan et al. 2006) and TB imposes enormous adverse economic impact. According to recent estimates, TB caused India to lose an estimated 340 billion US dollars (Goodchild et al. 2011). The country has 32.7% of the total population as poor (Sumner, 2012); TB can lead to catastrophic out-of-pocket expenditure (Rajeswari et al. 1999). It is imperative that oversight and management systems and ensuring political will at all the levels of government are key determinants of the success of the initiative (Nair et al. 2010). To achieve universal access to TB treatment, it is essential to diagnose all the persons with TB into the ambit of RNTCP network and provide directly observed treatment, short-course (DOTS) (Babu and Laxminarayan 2012; Control 2011). Capacity building of the healthcare professionals is important in prioritizing the autonomy of the screened individuals, patients under treatment, and the community. There is an immense and important role for the community engagement towards universal access (Table 4.2, Source: Authors' compilation).

Human Papilloma Virus (HPV) Vaccination Programme

In India, 132,000 women develop and 74,000 die from cervical cancer every year (Bhatla and Moda 2009). It is estimated that the risk of cervical cancer in India is 2.5 per 10,000 women in 1 year and risk reduction from vaccination is 0.00025, which translates that 4,000 girls need to be vaccinated to prevent 1 death (Aneja and Puliyel 2009). The mortality rate due to cervical cancer varies from 7.7 to 65.5 per 100,000 in India (I Mattheij et al. 2012a; Rastogi et al. 2007). There have been

Table 4.3 Data regarding cervical cancer and HPV vaccination in India

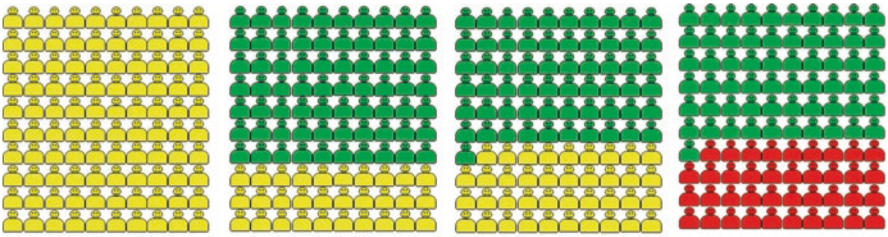
Cervical cancer and HPV vaccination	Statistics
Women at risk of cervical cancer (≥15 years)	469.1 million
Women who develop cervical cancer (annually)	1,32,000
Age-standardized cervical cancer rate	27/1,00,000 population
Risk reduction due to HPV vaccination	0.00025

recent debates on whether one should use HPV vaccine in India or not (Babu 2012a; I. Mattheij et al. 2012a, b). These perspectives suggest that the available evidence is neither in support nor rejection of using HPV in India (Table 4.3, Source: Authors' compilation). Notwithstanding this, the Indian unit of Program for Appropriate Technology in Health (PATH) initiated HPV vaccination trial in two states in 2009. The trial had several ethical issues with respect to informed consent, follow-up of the participants, and compensation for adverse reactions. Immunization in India was initiated based on the assumption that HPV vaccine is of greater public health importance, with an objective of considering to include the vaccine in national immunization programme. In this section we examine whether the use of HPV vaccine can be justified by using the ethics framework.

Beneficence

There is simply no sufficient evidence regarding presence of an effective vaccine against several strains of human papilloma virus (HPV), which can cause cervical cancer (Haug 2008a). The clinical trials and cost-effectiveness studies have provided evidence that two vaccines directed against HPV-16 and HPV-18 serotypes are in use (Kim and Goldie 2008). HPV serotypes 16 and 18 account for nearly 76.7% of cervical cancer in India (Kaarthigeyan 2012). However, protection offered by the HPV vaccine is only for certain types of serotypes for a shorter duration (Abby Lippman et al. 2007b). The vaccines have clearly demonstrated an efficacy of nearly 90% against preventing CIN2+ lesions containing HPV-16 and HPV-18 (Monie et al. 2008). Also, recent reviews suggest that the nine-valent vaccine directed against HPV types 6, 11, 16, 18, 31, 33, 45, 52, and 58 will increase the percentage of preventable HPV-associated cancers from 63.4% to 73.5% (Yang and Bracken 2016). For example, one vaccine is 91% effective against select HPV serotypes that cause adenocarcinoma and 83% effective overall against squamous cell carcinoma; another vaccine is 78% effective overall against HPV types that cause adenocarcinoma and 73% effective against HPV types that cause squamous cell carcinoma (5).

Our analysis (Fig. 4.3, Source: Authors) indicates that it is nearly futile to introduce HPV vaccine compared to more efficient measures such as improvements in screening and HPV testing, as well as preventive measures like improvements in personal hygiene and early detection; preventing all other risk factors through education will have effective results. Further, cost-benefit and/or cost-effective anal-

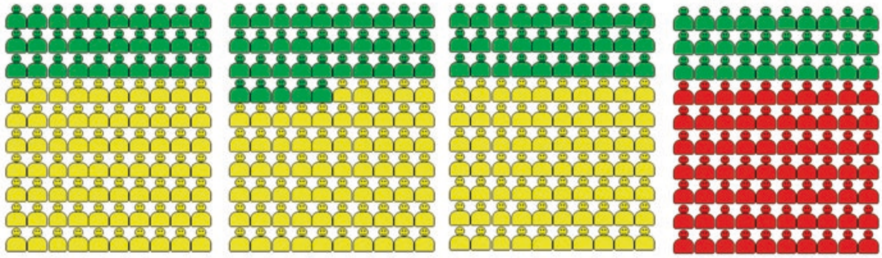


100% coverage with HPV vaccine

70% effectiveness

Vaccine efficacy is 87%

Actual protection is offered to only 61% by HPV vaccine against cervical cancer



50% coverage with HPV vaccine

70% effectiveness

Vaccine efficacy is 87%

Actual protection is offered to only 30% by HPV vaccine against cervical cancer

Fig. 4.3 Protection by HPV vaccine against cervical cancer determined by effectiveness and efficacy considering full and 50% coverage
Figure 4.3 explains the ethical concern, despite achieving an ambitious goal of 100% coverage of HPV vaccination in India; due to the effectiveness (70%) and vaccine efficacy (87%), only 61% girls are protected against cervical cancer, whereas the remaining 39% girls will not be protected against cervical cancer. Similarly, with 50% of coverage, 70% girls will not be protected against cervical cancer. Therefore, despite the high cost, there is no sufficient evidence to suggest complete protection

ysis has not been done for India to suggest that it is beneficial to introduce the vaccine under the national or a state programme. Inclusion of the vaccine in a state or national program violates the ethical principle of *beneficence*. It is because there is no evidence to support that vaccination programme can assure better prospects for the planning compared to more economical and safe methods of prevention (such as improvements in personal hygiene through education, improvement in sanitation), better screening, better diagnosis, or early treatment of HPV infection (Basu 2006).

Justice

HPV vaccine costs around ₹2700 per dose, and the recommendation is to take two doses in the 9–13 age group. Evidence indicates that vaccination requires further booster doses (Haug 2008b) and poses additional economic burden and challenge. Assuming three primary and equal number of booster doses are given to every girl in 9–13 age group, a cost of ₹16,200 is incurred by the government, translating to approximately ₹900 crores[1] (11 billion USD) spent on the vaccine at national level for one cohort of children in this age group.

Also, it is not clear how many booster doses will be needed and whether they will be safe in Indian settings (Lippman et al. 2007a; Haug 2008a). In addition, government's actions cannot be justified if it introduces HPV vaccine while no renewed comprehensive national efforts are taken to improve screening, diagnosis, and management of cervical cancer. The ethical principle of "justice" will be violated if it is targeted only to cater to the vulnerable individuals. Ethical resolution of these would involve having national vaccine policy that formulates ethical guidelines for introduction of new vaccines. There are no wider consultations with civil society organizations and community representatives to inform, discuss, and rationalize introduction of HPV vaccines. Therefore, vulnerable population is either petrified of the huge costs; even if people can afford, there is no convincing information. The recommendation of the experts whether HPV vaccine will be beneficial or not is also confusing. Simply put, there is no information to help the parents in deciding whether they should vaccinate or not.

The vulnerable community also is not part of the data collection process; and, therefore, available evidence is not generalizable to the entire country. As an analogy, the disease burden data is captured from mostly urban-based cancer registry (Babu 2009). Severe cases in rural areas may die at home before detection or die at hospital before diagnosis. Known as survival bias in epidemiology, this problem results in biased priority setting at the policy level (Babu 2009). The greatest challenge is to get the reliable data from people belonging to the vulnerable groups, especially in rural areas. Due to the inconstant estimates, and lack of data on extent of the disease, it is almost impossible to understand whether a HPV vaccination programme would decrease the imminent cancer burden in India (Babu 2012b).

The cancer registries and surveillance systems in India are incomplete, and, therefore, comprehensive coverage of every region in India is not done (Mattheij et al. 2012a). If the vaccine is to be used as part of the immunization programme, every subpopulation should be covered equally, the epidemiology of the disease should be known, the disease should be to justify its prioritization, and surveillance systems should be capable of assessing the impact of a vaccine intervention (WHO 2005). There are no sufficient details available on any of these requirements. To add to the despair, while the Government of India stopped the research on HPV vaccination by PATH (LaMontagne and Sherris 2013).

Ideally, governments should make decisions of introducing newer vaccines into national immunization programmes based on evidence on the disease burden. In the absence of such evidence, the decision might be guided either by expertise provided from international organizations or through advice given by experts and/or lobbyists representing private manufacturers. However, all such guidance can be subjective and biased depending on the priorities (Babu and Murthy 2011). For example, the use of condoms and maintaining genital hygiene are equally effective in preventing

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[1] The population in the age group was estimated from the data available from http://mhrd.gov.in/sites/upload_files/mhrd/files/statistics/PopulationProjection2016%20uated.pdf.

the HPV infection and subsequent predilection to cancer. There is no policy guidance or expert consultation whether the government should promote HPV vaccine or the awareness to use condoms and promote hygiene. In the absence of focus and prioritization by the policymakers, the vulnerable community is worst affected.

Respect for Persons

Evidences suggest there is violation for respect for persons in HPV vaccination programme; the rights of the person are not safeguarded. Individual's autonomy has been not respected. Policy guidelines stress the introduction of HPV vaccine, since it protects against cervical cancer, but the epidemiological evidence for the introduction of this vaccine in India is poor, and introduction of such vaccine is based on since other countries has started up such programme (Madhavi et al. 2010). Since the vaccine is expensive, some health practitioners advise that this can be used by the upper- and middle-class families, which is a clear disadvantage for poor families. Large trials regarding HPV vaccination have not been conducted in India, and approval in India for the introduction of the vaccine has been done based on small trials, and still there is no evidence for the number of doses required (frequency). In the trial conducted by PATH, autonomy has not been respected in the trial conducted in two states, and also no valid informed consent was taken. The trials in India have been criticized for unethical conduct (Sarojini et al. 2010; Ramanathan and Varghese 2010).

Therefore, there are multiple ethical challenges related to cervical cancer prevention. First, we do not know the cancer burden in females living in all the areas, especially in the east, far north, and most of rural India (Dhillon et al. 2011; Swaminathan et al. 2011). Second, as per the available patchy evidence, the cervical cancer rate is lower compared to other developing countries (Forman et al. 2017). In the absence of reliable data, surveillance system and monitoring mechanisms, and introduction of HPV vaccination programmes, the country would not get benefited from the vaccine. While in the absence of data, decision-making for introducing the HPV vaccine is troublesome; the State Governments of Sikkim, Punjab and Delhi have already gone ahead and implemented the HPV vaccination programme. Due to the present high cost of the vaccine, including it in the Universal Immunization Program (UIP) is highly contentious.

Resolution

The public health principles involved in introducing a new vaccine require that there should be satisfactory data available to prioritize the condition as an important health problem in India. The cancer registry should capture all the rural areas with expansion of the screening across the country. If the data suggests that intervention is necessary, studies should be done exploring the cost-effectiveness of personal hygiene, sanitation, early screening, and treatment and introducing a new vaccine. If the country/states decide to implement HPV vaccination, a register should capture all the adverse effects associated with the vaccine; in the case of an adverse event, an accepted compensation for the persons affected with adverse events of the vaccine is made available, and the vaccine should be cost-effective. The state and central governments should consider evidence before introducing the HPV vaccine. The country should have a policy on the HPV vaccination.

Disease Eradication Programmes

For illustration purposes of disease eradication, we have used the polio eradication programme here. Polio is an infectious disease caused by a poliovirus, which lives in the throat and intestinal tract. It is mostly spread through person-to-person contact with the stool of an infected person and may also be spread through oral/nasal secretions. Polio affected thousands of children in India and caused severe illness in thousands of children each year before polio vaccine was introduced. Although most affected people with the poliovirus have no symptoms, around 1 in 200 infected children could develop paralysis, which leads to permanent disability and even death.

In 1988, the World Health Organization (WHO) initiated global eradication of poliomyelitis by the year 2000. Eradication programmes aim for reducing the incidence of infectious diseases to zero and thereby completely exterminate the virus all over the world. Wild poliovirus, the strain of the virus responsible for causing the dreaded poliomyelitis, has not been found in India since 13 January 2011. Therefore, India is a “polio-free nation” for more than 7 years.

The momentous feat of polio eradication in India is accomplished by immunization with OPV. Currently, OPV and IPV vaccination schedule is practised in national programme in India.

Beneficence

There are two types of vaccine that protect against polio: inactivated poliovirus vaccine (IPV) and OPV. IPV is given as an injection in the leg or arm, depending on the patient’s age. OPV consists of a mixture of live-attenuated poliovirus strains of each of the three serotypes, selected by their ability to mimic the immune response following infection with wild polioviruses but with a significantly reduced incidence of spreading to the central nervous system (John 1976). Three or more spaced doses of OPV are required to generate adequate levels of protection against the disease. The OPV acts by producing antibodies in the blood to all three types of poliovirus and, in the event of infection, also produces a local immune response in the lining of the intestines, thereby stopping the poliovirus multiplication.

The administration of OPV itself can result in paralysis, termed as vaccine-associated paralytic polio (VAPP). VAPP is associated with a reversion of the vaccine strains to act more like neurovirulent profile of wild poliovirus. In a few instances, such vaccine strains have become both neurovirulent and transmissible and have resulted in infectious poliomyelitis (Minor 2009; John and Vashishtha 2012). Despite OPV causing paralysis in children continued for years, the country had to continue the polio eradication programme because the wild virus could have affected more children. At the least, it was estimated that about 60–300 VAPP cases occur every year although the numbers can be high and the programme has not made this information publicly available (Paul 2004).

Justice

No compensation was ever paid to the affected families, in which the children were paralysed due to OPV. Arguably, as long as the OPV is continued to administer, there will be few hundreds or thousands of children paralysed. As public health practitioners, another aspect of discomfiture results from providing very little or no information to the laypersons. The public is completely unclear about the benefits and risk due to the use of two different forms: OPV and IPV. Hundreds of vulnerable families who accepted the vaccine due to the perseverance of the ongoing programme might have had a paralysed child due to the vaccine itself (Yash Paul 2005b).

Polio eradication programme was very prolonged taking most of the efforts of health workers in high-risk states such as Uttar Pradesh and Bihar. As a result, the focus provided to routine immunization programme and other public health programme was poor and resulted in building up the huge cohort of unimmunized children for other diseases. Also, it led to the fatigue and decreased performance of the health workers (59). Running the vertical programmes such as disease eradication programme drives away the primary healthcare resources and results in imbalance and weakening in healthcare services (Gorman 2013). Also, the constrained health budgets of governments are better utilized for finding marginal cases under disease eradication programmes; other local health problems will be neglected (Caplan 2009; Yash Paul 2005a).

Respect to Persons

Practically, no public health programme takes informed consent from persons after explaining the benefits and potential risks of the programme. Hence, poor informed consent from the parents is another important ethical concern of protecting the autonomy of parents; they were provided with no or limited information regarding harmful effect of oral polio vaccine (Yash Paul and Dawson 2005). During polio eradication programme, several parents had confusions regarding intensification of the frequency of the programme (Hussain et al. 2012). With the aim of eradication, in many of the countries, children are exposed to high risk of multiple doses of vaccination since the recordkeeping is poor in such countries (Caplan 2009). In some parts of the world, ensuring the autonomy for laypersons created hassles to the programme managers, resulting in people opposing the vaccination and resulting in recurrence of disease due to persistence of reservoir of infection. These instances from the USA, UK, and Canada have guided the public policy efforts in India to remain silent on the patients' rights and autonomy in order to reach the goal of eradication (Caplan 2009).

Resolution

For some of the infectious diseases, seeking elimination and control measures could be effective with due credence to following the ethical principles. What was thought to be a daunting task by the Global Polio Eradication Initiative (GPEI), India eliminated wild poliovirus (WPV) transmission. While this is a matter of pride for all the Indians, ethical guidance seeks that we maintain the data regarding VAPP and Vaccine Derived Poliovirus (VDPV) publicly and compensate the victims of the adverse effects of the vaccine. Ethical concerns involving disease control/elimination programmes can be prevented in the future if the policymakers give due credence to respecting the rights of people.

Conclusions

Public health programmes face numerous ethical issues while practising according to ethical principles. We examined the ethical principles of respect for persons, beneficence, and justice, in the implementation of three public health programmes in India. These principles have been primarily used as a framework for evaluating research on human participants. We apply these principles in the context of public health policy promotion and programme implementation in India, and our analysis might apply for the low- and middle-income countries (LMICs). Public health practice in the modern world features numerous ethical dilemmas (Attaran 2005; Detels et al. 1999). We understand that governments and international agencies would have faced these dilemmas while implementing public health programmes including the examples used in the chapter. The present chapter is not a critique of existing public health programmes, but we enforce that there should be ethical focus for their improvization, so that there will not be violation of ethical principles. The analysis indicates that most of the ethical violations may be prevented if any of the ethical frameworks are adopted, and we have presented such framework comprising of respect for persons, justice, and beneficence which is applied before practice.

Whether done as an institutional policy or not, public health professionals can learn from the personal experience and can collaborate using ethics as a fundamental component of decision-making. If the fundamental principles of ethics, namely, beneficence, non-maleficence, and autonomy are followed, most of the challenges can be reduced. The ethical actions needed are not exhaustive subsumed in these three principles; many other actions such as population-level utility, establishing accountability, ensuring competency and capabilities, etc. will aid in resolving ethical issues in public health practice (Baum et al. 2007). Also, public health programmes should ensure that privacy and confidentiality are maintained and education and ethical training with support are provided to public health practitioners.

We recommend piloting the application of the principles of respect for persons, beneficence, and justice as a suggestive template for guiding on ethical values for public health programmes before scaling up. These principles should be shared with policymakers and used in taking public health programmatic decisions. For resolving ethical issues of any public health programmes, there must be a role of ethical theories and principles, ethical decision-making authorities, ethical committees, public, and other stakeholders. In keeping with the spirit of the Belmont's report, the focus of the public health programmes can be aimed towards preventing gross unethical treatment of humans. The policymakers can ensure that public health programmes are evaluated against some ethical framework before implementation in India. In the absence of clearly developed ethical frameworks, there is a perception among the health managers that they are doing public good by implementing the public health programme and hence minor aberration or side effect to few individuals is tolerable (if not justified). Often, the stance of doing public good is mistaken as being ethical. It is important that the public health practitioners take proactive measures than being reactive to ethical violations. Towards this, we hypothesize that using pre-emptive ethical screening for health programme development and implementation might limit many violations. As a first step, we propose that existing public health programmes can be reviewed through this framework. Currently, the role of health policymakers is to make decisions on behalf of people (for their good) in a low- and middle-income country including India. The focus of using an ethical framework shifts the decision-making regarding accepting or rejecting public health intervention to the individual level by people themselves, and health managers need to merely facilitate it. This is a daunting task, and we are aware of the limitation; however, using the ethical principles is not a matter of chance or choice but of absolute need for protecting *the public* in public health.

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Chapter 5
The Endosulfan Tragedy of Kasaragod: Health and Ethics in Non-health Sector Programs

Adithya Pradyumna and Jayakumar Chelaton

Abstract It is now over 15 years since the aerial spraying of endosulfan over cashew plantations was stopped (and subsequently banned) in Kasaragod, Kerala. Thousands of individuals have been affected in permanent ways in the exposed villages. As there are potentially several important lessons to be learned from this experience, it would be useful to reflect on the decision-making that led to the design of the spraying programme and examine the efforts that are being made towards managing these health impacts. Through the lens of public health ethics, this chapter seeks to explore the design and implementation of the relief and remediation programme at Kasaragod, the identification of and support provided to victims and the role played by actors including experts, local community and local government. The chapter concludes with a discussion on approaches to predict and avoid such occurrences through Health Impact Assessment and the involvement of local people and the challenges that might prevent the adoption of such approaches.

Keywords Environmental health policy · Environmental health ethics · Environmental justice · Health Impact Assessment · Local health systems · Hazardous exposure

Introduction

India has had its share of anthropogenic environmental health disasters over the years. The ones most devastating and vivid from recent memory are the Bhopal gas tragedy of 1984 and the endosulfan tragedy at Kasaragod (until 2002). Both of these affected several thousand people locally. Though several books and articles have been written about the Bhopal gas tragedy, it still does not do adequate justice to the

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medical and public health lessons that have been (or should have been) learned from such adverse events (Pradyumna and Gaithonde 2013). Efforts made by various actors over three decades in Bhopal include identifying and treating victims, organizing medical care, patient management and follow up, creating awareness, legal action, compensation and rehabilitation efforts, livelihood programmes and research projects among other things. Yet, much less has been documented about the endosulfan tragedy, possibly because it was not a sudden accident (like the Bhopal gas tragedy) but a situation that was insidious and worsened over years. It is now over 15 years since the aerial spraying of endosulfan over the cashew plantations was stopped (and subsequently banned) in Kasargaod, Kerala. While the environmental impacts of the spraying were felt soon after the operations began in 1976 with the disappearance of bees (in other words, the "health" of the bees), the human health impacts were noticed by the early 1990s by a local physician (Department of Health and Family Welfare 2011; Rajkumar 2002). Thousands of individuals have been affected in permanent ways in the exposed villages with birth defects and mental retardation among children who were born after the initiation of spraying operations and increased incidence of abortions and gynaecological disorders among women. According to government reports, by 2011, at least 312 individuals had died due to health effects of endosulfan [cited in (The High Court of Kerala 2015)].

This chapter discusses the relief and remediation programme for the victims, families and communities and examines the space for health considerations in decision-making in non-health programmes (in this case, the aerial spraying programme). The authors are environmental health practitioners engaged in interrogating ethical implications and lessons of environmental disasters. Both the authors have been closely involved in the endosulfan tragedy in different capacities. JC has been actively engaged in the "Ban Endosulfan" campaign since the late 1990s as part of an NGO called Thanal and has participated in consultations on this issue. AP, as a community health intern, initially visited the affected areas in 2008 under the guidance of JC. While AP has been following up through an analysis of this issue in the media and academic spaces, JC has been following court cases, judgements, relief programme updates and governmental decisions. This chapter thus draws on the authors' close engagement with the campaign, interactions with local community, consultations with concerned authorities (government and others), a historical tracing of different moments in the unfolding and management of the event as well as an analysis of existing academic literature.

Relief and Remediation: Response to the Crisis

As the tragedy is a matter of history, it would be appropriate to first look at the relief, remediation and rehabilitation initiatives that have been undertaken at the local level. The history of these efforts provides important insights on how various state and non-state actors diagnosed and responded to the tragedy, which itself gives insight on priorities, ethics and technical challenges. The relief efforts continue to unfold even as of today. There have been a range of initiatives, both sporadic and systematic, by various actors, both local and international, at different periods of time. Also, in addition to the use of public money, donations were sought through a dedicated website by the Endosulfan Victims Relief and Remediation Cell for relief and remediation measures.

Around the time when court and government orders were made for banning aerial spraying of endosulfan in Kasaragod in 2003, medical camps had been initiated in the affected villages by the Health Department and Calicut Medical College with the support of the District Panchayat and administration. Local groups also initiated efforts towards remediation using money and other materials collected locally from friends and well-wishers from abroad. The money was reportedly used for supporting medical expenses, repayment of debts and supporting basic needs, according to a key informant in the community. Local people recognized that these interventions were only limited in their reach and temporary but considered them important from a “psychological” perspective (District Panchayat, Kasaragod 2005a). The recognition that the distress faced by thousands was potentially preventable may have had a great mental impact on those who were ill and their caregivers. Such sporadic efforts may have played a critical role until systems kicked in.

Based on petitions from the concerned local groups, a consultative workshop was planned by the Kasaragod District Panchayat in 2005. This consultation on the relief and remediation plan was co-organised with various NGOs and attended by local people, academicians, doctors and panchayat members from the affected villages. The plan itself covered policy, social, health, environmental, financial and operational aspects (District Panchayat, Kasaragod 2005a). While the creation of the Endosulfan Victims Relief and Remediation Cell was taking time, the chief minister of Kerala also announced a budget allocation from the state government towards these activities. This was in addition to resources that were being raised by district and gram panchayats, NGOs and the Social Welfare Department (Government of Kerala 2006).

The Endosulfan Victims Relief and Remediation Cell was formally initiated at the headquarters of the Kasaragod District Panchayat in 2007. Meetings among 34 members (including panchayat and civil society members) were held once in 2–3 months, where issues of budget allocation, remediation measures and future activities were discussed. The group decided to allocate Rs. 37 lakh towards compensation and medical care, Rs. 7 lakh towards procuring aids for the people with disability and Rs. 6 lakhs for research (Pradyumna 2009). It was also felt that the allocated amount of Rs. 50 lakhs was inadequate (keeping in mind continued submission of applications for relief) (Venugopal 2008). While this allocation was decided through consensus among the Cell members, it would be useful to further document how the decision was made. In addition, besides the announcement of the budgetary allocation, there was no clear intent of sustained financial support to the relief activities over the coming years.

The Social Welfare Department had previously given a monthly assistance of Rs. 250 to caregivers/families of persons with severe disabilities resulting from endosulfan exposure, in addition to the pension of Rs. 250 already being given to disabled persons in Kerala (Government of Kerala 2006). In 2011, the monthly pension was increased to between Rs. 1000 and 2000 (based on the "category" of illness described later). All affected families were also provided with subsidized rice at Rs. 2 per kilogram (Government of Kerala 2006), as was done for families below poverty line. Caregivers were also later given a monthly pension of Rs. 700 in the case of bed-ridden patients and those caring for persons with mental retardation (The High Court of Kerala 2015).

The government has provided Rs. 50,000 for each family when an affected person in the family died (Government of Kerala 2006). At that stage, families of 135 victims got this compensation. People continued to die due to chronic ailments, and lists continued to be prepared (Venugopal 2008). In 2008, an officer at the Cell reported challenges in future compensations due to fund shortages (Pradyumna 2009).

The National Human Rights Commission (NHRC), based on fresh field reports in 2010, investigated the ground situation and made recommendations to the central Kerala state governments. These stemmed from perceived "little impact" of the relief and remediation. In the list, there was a suggestion to compensate Rs. 5 lakh to next of kin of the deceased and seriously ill victims and 3 lakh for those with disabilities. This is besides other recommendations to support medical care and basic support (NHRC 2010). The estimated amount needed to fulfil these recommendations was Rs. 250 crores, as calculated by the Kerala state government, which the high court perceived to not be an unmanageable amount (The High Court of Kerala 2015).

As of 2011, 178 families had received the compensation. At that stage, a proposal to increase compensation for the seriously ill to Rs. 1 lakh was made (Department of Health and Family Welfare 2011). Part payments were initiated in 2015 (The High Court of Kerala 2015) of initially Rs. 46.1 crores to 3549 victims, Rs. 44.6 s to 3435 victims in the second instalment, and Rs. 42 crores to 2728 victims in the third instalment. In 2017, the Supreme Court directed the state to release the entire undisbursed amount of compensation to the affected persons in response to a public interest litigation filed in 2012. Overall, it is unclear how various amounts for compensation, pension and support were calculated and what the proposed duration of the pension was, and these are important from point of view of the affected families, ethics and programme management.

There were other actors too providing relief on a sporadic or consistent basis. Solidarity Youth Movement (SYM) provided food and other basic provisions on a monthly basis since 2007 (but it is unclear till when it continued or how many families were supported. It likely was discontinued soon after state interventions began). They also constructed houses for some of the affected families who didn't have proper housing. Medical camps and paramedical care were also reportedly supported (Pradyumna 2009). Some of the children were also supported financially for higher education. Unfortunately, details of the support provided are unavailable. The role of nongovernmental actors has always been important in disaster relief and rebuilding, and if these efforts are systematically documented, impacts of programmes can be determined.

The Sarva Shiksha Abhiyan made efforts (at least on a pilot basis with 108 children) for families with physically or mentally challenged children. Weekly meetings and parent trainings are being conducted, and the necessary aids are being provided to the children after thorough assessments. Exercises were also being taught and development of social skills was also encouraged. Medical and rehabilitation measures are also being provided at these centres (Pradyumna 2009). In addition, BUDS schools for differently abled children were initiated in the affected areas (Special Correspondent 2011), and reportedly nine were opened. Affected children and those in their 20s were also supported in the development of social skills and occupational and rehabilitative therapies. It was also a relief for caregivers. According to a key informant, over a period of time, these schools have lost funding support from the local government, and there is significant dropout of students, and now local groups are considering starting their own schools. Even in 2016, a BUDS Special School was initiated with a special fund provided by the National Bank for Agriculture and Rural Development (Correspondent 2016). While the size of school had grown soon to 115 students, there are already reports of poor compensation for teachers. There has also been a move to not admit affected persons over 18 years of age (Varier 2016).

Though there have been challenges even in initiating support services such as community-based rehabilitation, special schools and pensions, these have been initiated at least in some areas (Pradyumna 2009). Early on, it was felt by some that the relief was not adequate and that the main focus was on compensation rather than protecting the living, a view that was not shared by the district administration. Others felt that the treatment provisions were good, but community-based care and rehabilitative services were not adequate (Venugopal 2008). Now, newer schemes for support, such as subsidised power supply, are being considered (The Express News Service 2017).

The Role of Health Professionals: Assessing Public Health Impacts and Responses

It was a local health professional who identified the unexpectedly high number of cases of congenital anomalies and reproductive health problems in his practice. He systematically documented the cases and communicated his findings through popular and professional magazines in 1996 (Joshi 2001). Other medical and public health professionals also contributed to the campaign by making independent technical enquiries and preparing reports (Centre for Science and Environment 2001; Quijano 2002; Rajkumar 2002). Physicians can have great insight about local health trends and have an important role to play. Often this could be challenging due to the presence of powerful groups with vested interests.

In the civil society consultation on the remediation plans held in 2005, health professionals participated actively. Perspectives from various systems of medicine, allopathy, ayurveda and homeopathy, and also public health were shared by the experts. This included information about potential health impacts and opinions on approaches to treat and organize relief plans. A proposal was also made that a technical team will visit Bhopal to understand the approaches used for documenting victims, treating them and systematically following them up over a period of time (District Panchayat, Kasaragod 2005b). This was indeed a very good idea, so that precious time is saved through the adoption of lessons learned in Bhopal and also use financial and human resources more efficiently and effectively. However, a key informant stated that the trip to Bhopal was not done, but a few volunteers from Bhopal did visit Kasaragod briefly.

"Health" suggestions given at the consultation were eventually included in the plan document prepared by the District Panchayat of Kasaragod (District Panchayat, Kasaragod 2005a):

- Conducting door-to-door surveys to establish data at individual level (undertaking all procedures at ethical levels prescribed by the ICMR).
- Identification of the affected to initiate relief measures.
- Listing appropriate treatment options for each type of health impact.
- Establishing a system for continuing medical assistance.
- Setting up a surveillance system for screening cases.
- Initiating community-based monitoring and rehabilitation of the affected with the support of Calicut Medical College.
- Creating special schools with appropriately trained teachers in affected areas.
- Supporting services at schools and anganwadis at local level for affected children, creation of day care centres at ward level and special assistance for mothers of affected children.
- Supply of appropriate aids and devices to the differently abled.
- Uninterrupted supply of medicines for the affected.
- Special card given for waiving off medical costs.
- A relief programme for caregivers in the locality.
- Measures for children who have been orphaned.
- Sensitive approaches to be used for identifying and treating problems affecting women.
- Health assessment and relief measures for workers in the plantation.
- Nutritional supplementation through involvement of local self-help groups.
- Assess training needs at local and district levels.
- The medical department should become a member of the proposed Endosulfan Victims Relief and Remediation Cell (District Panchayat, Kasaragod 2005b).

Pariyaram Medical College Hospital was initially entrusted with the responsibility of providing surgical interventions for those victims who needed it. This was supported by the government (Government of Kerala 2006). The Cell made special provisions to make seizure and psychiatric medications available at each primary health centre (PHC) in the affected areas due to the relatively high number of such cases in these areas (Pradyumna 2009).

Additional studies were commissioned in 2010 by the state government to further understand the health situation in impacted areas and the environmental and long-term impacts. It was further confirmed that reproductive health conditions, experience of undergoing surgeries among younger people, child mortality and congenital anomalies were significantly higher in endosulfan-exposed populations [cited in the Department of Health and Family Welfare 2011)].

Systems were then put into place to ensure complete and sustained care and support to officially identified victims. This included (Department of Health and Family Welfare 2011):

- A treatment smart card: to provide cashless registration and treatment and to have the data of the patient accessible online at the empanelled hospitals. This had been provided to 4273 by mid-2011, and software for recognizing and using smart cards had already been installed in 11 empanelled hospitals, and appropriate training for staff members was also being given.
- Even before the operationalization of the card, free treatment was possible for enlisted patients with a letter from the DMO. Such provisions become important to improve access and reduce the burden on the victims, especially in the times of the "Aadhaar". Prompt payments for services were a key factor to continue trust between partners, and it was claimed that payments were prompt in 2011.

Furthermore, "mobile medical units" were set up to provide home-based care for identified patients. These teams were multidisciplinary, including doctors from various streams of medicine, physiotherapist, mental health worker, special trainer and speech therapist. Three such teams had been set up as of 2011 to serve the 11 affected villages (Department of Health and Family Welfare 2011). In addition, the BUDS schools provided occupational and rehabilitative services to the children attending those schools (Special Correspondent 2011). However, there is a need for greater documentation and evaluation of these experiences to facilitate learning.

Palliative care to provide relief to the very ill victims was also being supported. Two nurses, each specially trained in palliative care, and one physiotherapist were posted in each of the affected panchayats. The necessary equipment was also provided. A vehicle was provided at each panchayat for local travel of this team (Department of Health and Family Welfare 2011).

Finally, approaches to strengthen local health systems were strategized. The proposed measures were (Department of Health and Family Welfare 2011):

- Additional salary incentives for doctors to work in primary and community health centres in affected areas of Kasaragod.
- The physiotherapist assigned to the panchayat will also be affiliated with one PHC which will have a physiotherapy unit.
- Modernisation of the two large district hospitals was undertaken, which included fully equipped physiotherapy unit, advanced lab investigation facility and training centre for special education.
- A plan for making more ambulances available was also proposed.

It was reported that these were undertaken at a cost of over Rs. 1.3 crores (The High Court of Kerala 2015). A key informant stated that the initial steps in these aspects were positive, with convergence of systems of medicine, support of doctors to the Cell and diverting of more resources from the National Rural Health Mission (NRHM) to these areas keeping the special need in mind. An endosulfan nodal officer was also appointed, who helped bring evidence into discussions and decision-making to reduce further threat from existing stocks of endosulfan locally, with support from the revenue officials and state pollution control board in 2012. The Food and Agriculture Organization guidelines for managing obsolete pesticides were used, and the initiative was titled Operation Blossom Spring (Misra and Rehman 2012; Staff Reporter 2012). Reportedly, research was conducted on secondary data on the impact of endosulfan which helped further planning and decision-making, but it is unclear whether these studies are available in public domain. Decontamination is an important and expensive process and has been shown to be complicated especially in other cases in India (such as at Bhopal and Kodaikanal).

Identification of Victims: Comprehensiveness and Associated Challenges

Based on initial understanding, at least 12 panchayats in Kasaragod were affected (District Panchayat Kasaragod, 2005b). However, in a 2011 state government report, the total number of affected villages is mentioned as 11 (Department of Health and Family Welfare 2011). It is unclear from these documents how the decision on “affected” villages was made. The adopted methodology should be made available for public viewing as there is scope for great learning for students and practitioners of public health. Even lesser is known about the impact of the aerial spraying programme on villages in the neighbouring Puttur taluk of Karnataka state. Endosulfan has become synonymous with Kasaragod, and Puttur may have been lost in translation. Communities in the latter had been demanding for victim identification even as of 2015 (Sanjiv 2017). This paper has not explored the impact and relief interventions in Puttur, which itself would be a very important and useful exercise.

When the Kerala chief minister wrote his letter in 2006 declaring budgetary allocations for endosulfan relief, the Health Department had identified a total of 1996 victims, of which reportedly 103 were “severe cases” (Government of Kerala 2006). Of these, 63 had needed surgical care, which was provided at Kasturba Medical College, Mangalore, and the costs for the care and hospital stay were covered by the Cell (Pradyumna 2009). Local primary health centres were engaged in identifying individual victims at village level by the Cell. By the end of 2008, reportedly over 250 aids such as wheel chairs and hearing aids were distributed to the identified victims. Also, 123 families had received lump sum compensation towards death of affected persons, and a further 300 families that had applied had been approved for similar compensation (Pradyumna 2009).

Only in 2010–2011 was an “active” search conducted for victims through house-to-house surveys and 17 specialty medical camps (at least 1 in each affected panchayat, to further identify, confirm, treat and provide smart cards). This effort involved 300 doctors from medical colleges and primary health centres. These camps appear to have been organized well, with detailed registrations managed at several counters, general practitioners screening and appropriately referring cases to specialists and specialists in separate rooms assisted by nurses. Arrangements were also made for basic lab investigations, dispensing medicines, follow-up and also lunch and refreshments for camp attendees. Assistance was provided for transporting patients to the camp and back to their villages, supported by local health workers and the village panchayats. A total of 15,698 people attended the camps (Department of Health and Family Welfare 2011). It is unclear why it took few years after the setting up of the Endosulfan Victims Relief and Remediation Cell to organize this camp, keeping in mind the potential medical and social costs that people may have already borne. However, a proposal was put forth, and the implementation was started in 2011 to waiver medical loans of impacted families (which were on average Rs. 50,000 among households which were impacted, as identified through the house-to-house socioeconomic survey) (Department of Health and Family Welfare 2011). As of 2015, the government reported having waived loans of 1191 applicants (The High Court of Kerala 2015). The “lag time” in relief has severe implications at various levels for impacted families of any disaster. Also, the high court was very clear on not making loan waiver lists public due to fear of stigma on those households (The High Court of Kerala 2015).

In addition, the full range of impacts is unfathomable. For instance, there is a case of a father leaving the family due to the birth of three children with disabilities (Venugopal 2008). People of all ages and gender have been affected to varying degrees. Some children have such disabilities that they constantly need the presence of a caregiver (usually the mother in the case of impacted families in Kasaragod), and so livelihood was severely affected (Venugopal 2008). How does one quantify “broken families” and “lost time”? It is precisely these types of challenges that necessitate critical learning from the Kasaragod endosulfan tragedy so that any future disasters are managed much better and even prevented all together wherever possible.

At the medical camps held in 2010–2011, the inclusion criteria set for endosulfan victims were these (Department of Health and Family Welfare 2011):

- History of exposure.

  Occupational
  Nonoccupational
  Mother to child

- Established health effects of endosulfan based on over 140 peer-reviewed papers on the health effects of endosulfan. This included impacts on:

  Nervous system
  Endocrine system
  Reproductive health
  Genotoxic and mutagenic impacts

  Carcinogenicity
  Immune system
  Others

- Benefit of the doubt for inclusion in the list was given to the patient.

Despite perceptions among political leaders and others that almost all deaths in the area were being inappropriately attributed to endosulfan, it was still felt that erring on the side of the people was the better thing to do, as they felt that the victims should not be missed, and in addition, the affected people were "so poor" (Venugopal 2008). As in the case of most environmental tragedies (for instance, Bhopal gas tragedy and climatic disasters), the bulk of the impact is faced by the poor.

It may sound mundane, but it never gets old: prevention is better than cure. As the tragedy was not prevented, the costs of including even those who may not have been victims will have to be borne, as it would be unethical to miss even a single victim. The costs of relief and rehabilitation were probably a lot more than the savings of the aerial spraying programme. Minimising negative externalities are critical for distributive justice.

A total of 3435 persons were initially identified as probable victims of endosulfan exposure. For patients who were unable to make it to the camps, but had been identified in previous surveys and camps, additional follow-up visits were conducted by medical officers, and using the same criteria, 838 more persons were identified. Support and benefits were being received by these 4273 persons as of February 2011 (Department of Health and Family Welfare 2011). For those persons who were neither identified in previous surveys nor had attended the camps, a system was set up as follows: applications can be submitted at any time by patients to the Endosulfan Victims Relief and Remediation Cell (which was now called Sneha Santhwanam Cell), which will then be forwarded to the District Medical Officer. This officer in turn instructs the local PHC medical officer to examine the patient and provide a report (or alternatively directly visit a nearby government health institution, according to a key informant). Based on that, a second level of screening and allotment to different departments is done by a district team (according to a key informant), and then the DMO then refers the case papers to a committee of experts which will review submissions in periodic intervals to make a decision about the case. Of the 1097 applications received until February 2011, 738 were examined by the committee, and 257 were included as probable victims of endosulfan. This list of patients was further sent to the District Collector for address approval, so that support can be initiated (Department of Health and Family Welfare 2011). In 2013, two additional detailed guidelines on temporality and biological plausibility were added to assess cases, and based on this, an additional 337 probable victims were added to the list (according to a key informant). This robust system was essential to ensure the best possible screening for potential victims. However, it is unclear how the information regarding the camps was communicated to local people. That would be interesting to learn towards developing a protocol for future remediation programmes in India and elsewhere. In 2015, the high court in Ernakulum expressed satisfaction at the systems in place for victim identification (The High Court of Kerala 2015).

After a gap of 4 years, a camp was held in 2017 to assess new applicants to the remediation programme, and this was attended by 3884 people. It was also felt by members of the Cell that it would be useful to institute a tribunal for addressing grievances of victims (The Express News Service, 2017). It is unclear why there were gaps in the reviewing of applications, as systems had been set up quite well.

The Role Played by Local People and Local Government

It was indeed local people who initially recognized the problem. A local journalist Shree Padre first wrote about this issue. Then it was a local physician, Dr. Mohan Kumar, who documented cases in his area and wrote about it in various forums. Ms. M.K. Leelakumari Amma, who previously worked with the Agriculture Department at village level, took legal action at a local sub-court due to deterioration of health of her children and herself (Pradyumna 2009). Local protest groups such as Endosulfan Spray Protest Action Committee (ESPAC) and Endosulfan Virudha Samithi (with support from established NGOs) also took the campaign forward (District Panchayat, Kasaragod 2005b). It was the local court's order for temporary stoppage of spraying (in 2001), the high court's support to that judgement (in 2003) (Department of Health and Family Welfare 2011), and pressure from people that led to the ban at state level.

Creating awareness and mobilising local people about relief activities in affected panchayats were done largely by the local self-government through oral communications, letters and notices. While it was perceived that some households may have been missed during the home visits for notifying about relief activities, it was felt that most households were covered as local people knew affected households and that multiple communication methods ensured good dissemination. It was also perceived that following the initiation of relief activities, the presence of activists reduced and that politicians had taken over the oversight of the activities (Venugopal 2008). No lifespan was decided for the Cell, which was opined to continue to function as long as a need was felt by the people (Department of Health and Family Welfare 2011; Pradyumna 2009).

There were also proposals in 2011 to start a rehabilitation centre (or village) for those victims who did not have caregivers, vocation training for those victims with physical handicap and a residential special school with day care facilities for those intellectually challenged children (Department of Health and Family Welfare 2011). A key informant stated that 25 acres of land had been transferred to the Social Justice Department and designs had been approved, and it is progressing.

The relief and remediation activities have mobilised resources from various departments including Health, Civil Supplies, Social Welfare, Local Self-Government and Education (The High Court of Kerala 2015). This also corresponded with the presence of various sub-committees in the Endosulfan Victims Relief and Remediation Cell at Kasaragod. It would be useful to document the convergence processes of this multi-stakeholder experience.

Another aspect that needs to be looked into is the repeated "surveying" of the population. Around the year 2000, in response to civil society pressure, 11 commissions were appointed by the central and state government to understand about the situation in Kasaragod. In parallel, enquiries were being made by the local NGOs and activists (Department of Health and Family Welfare 2011). Subsequently, several surveys were also conducted to identify victims. It is unclear how these repeated enquiries may have impacted local people. Also, protocols to respond to putative disease clusters exist in literature, especially for cancer clusters (which perceived to be linked to toxic chemicals) (CDC 2013; Goodman et al. 2014). It was felt by the Kerala Government that the ICMR report was an important one that laid to rest most doubts about the case (Department of Health and Family Welfare 2011). It could be considered whether such a cluster examination team should be set up at ICMR for any future cluster reports from various parts of India. A key informant stated that activist-led follow-ups of initiatives became more visible and the district administration did not receive as much support from the state to implement recommendations of the NHRC.

To summarize the role played by various actors, a local journalist recognised the potential hazard; a local physician recognised the biomedical problem; local people came together to form a campaign and to arrange for relief; some local people registered cases; the state government responded to court orders and took actions; local government helped bring various stakeholders together to design a relief and remediation programme, and this was then implemented using state and local resources, with the health systems contributing in implementing the programme; and finally local groups and the NHRC ensuring some oversight on the progress of these measures. To summarize key arguments of this section, the relief and remediation programme at Kasaragod was imperative. The lives of so many families had been so deeply affected, and providing support was the least that could be done. However, even while this case shines as a beacon of hope for several affected regions in India, it was not without its share of technical, logistical and ethical challenges. The constant pressure by local people, scientists and technical groups, and court orders, and the electing of a sympathetic chief minister contributed to the planning and implementation of this programme. Values of social justice have been considered to ensure free treatment and additional support to victims and caregivers. Medical professionals and advisors, over a period of years, have been able to refine the system for identification of victims and subsequent care, which is very important if justice has to be ensured. Unfortunately, victims from some areas will be missed (for instance, those from neighbouring taluks of Karnataka and those who migrated). There are no clear measures that have been proposed for them. It is also unclear to what extent funds collected by local groups were utilised for the welfare of the affected as there are no documents in the public domain about this. All in all, the history of the relief programme is worth documenting in greater detail through robust evaluations (using realist lens) to help develop future public health policies.

Decision-Making in Designing Programmes of Other Sectors: Reflections

"But so far we do not have concrete and scientific evidence that will stand in a court of law which will squarely implicate the PCK (Plantation Corporation of Kerala) and the producers of endosulfan" was the statement made by a district-level government official (Venugopal 2008). A similar comment was made by the Indian delegation who were reportedly the only country against the ban on endosulfan, stating the lack of scientific evidence of harm (NHRC 2010). In addition, a 2011 petition at the high court in Ernakulum by the workers stated that endosulfan did not cause the effects seen in Kasaragod (The High Court of Kerala 2015). This was unfortunate as it was clear from an epidemiological perspective that aerially sprayed endosulfan was the culprit. In effect, this may have less to do with science and more to do with other drivers, as was recognised by the NHRC (2010).

In 2010, Mr. Achuthanandan, the then Chief Minister of Kerala, wrote a letter to the Prime Minister of India urging India's support towards the banning of endosulfan at the Rotterdam Convention as India had not supported the ban in earlier meetings potentially due to the endosulfan export market in India and its associated lobby (Achuthanandan 2010). This letter was also in response to a letter sent by the Endosulfan Manufacturers and Formulators Welfare Association to the Prime Minister maligning the work and credibility of scientists and NGOs in establishing endosulfan as the causative factor of adverse health effects in Kasaragod. He added about the potential long-term contamination and intergenerational impacts of the pesticide exposure too. He requested the search for safer options in the interest of people and the environment (Achuthanandan 2010). While the union agricultural minister claimed that several states wrote to him to not get endosulfan banned, it became clear through a right to information enquiry that none of the state governments wrote to him, and it was actually groups related to endosulfan producers and users primarily from Gujarat who did (Misra 2011).

At a recent event on endosulfan at Kasaragod which was attended by the chief minister of Kerala, a former worker with the Plantation Corporation of Kerala was holding a placard in support of the use of endosulfan and was subsequently jailed. The chief minister's words were that no one is "scared of them" (Kayyar 2017). This statement clearly reflects the issue of "power" in the context of decision-making. Just like in research ethics, where efforts are made to protect the subjects as the researcher is perceived to be more "powerful", the same should hold good for developmental interventions. Economic growth may be important for generating livelihoods, but it can be done in a way that is conscious of people's health and environment sustainability.

Currently there isn't a clear legal space for open discussions with local people for proposed interventions of this nature. With the existence of the 73rd and 74th amendments to the constitution, the gram sabha in rural areas and the ward sabha in urban areas should be forums for these kinds of discussions. However, these are rarely used, either by project proponents or by local people. An approach that is being used is to critique the draft EIA reports for projects and present the findings of the critique at the public hearing (either orally or in writing, if they have them). For other projects, it is entirely up to the proponent to invite health experts to participate in the proposal development and assessment. Some private companies take it up as a matter of internal policy (and to be consistent with guiding principles such as the Equator Principles) (Birley 2011).

Resnik listed the key principles of environmental health ethics as human rights, utility, justice, animal welfare, stewardship, sustainability and precaution (Resnik 2012). The issues of human rights and precaution have especially been cited by the NHRC in their recommendations document for two aspects: when the temporary ban was made by the high court (also see (The High Court of Kerala 2015)) and subsequently when several developed countries from across the world banned it (NHRC 2010). The NHRC has an important role to play in environmental health ethics, but so far the role has been remediation rather than prevention and mitigation. It appears that all principles were violated in the design of the spraying programme. Fortunately, in the relief and remediation programme, most of these values have been incorporated. This list of principles is useful in conducted HIA for future programmes with potential health impacts. For the case of Kasaragod, technically, the stoppage of aerial spraying was probably as important (or more) as the ban on endosulfan itself. If the PCK had continued the spraying programme with another pesticide, it is likely that a new set of health and other effects may have been seen. It was important to mitigate the exposure and the hazard.

Towards Reducing Avoidable Disasters

“Are not the perpetrators out in the open?” asked a journalist in his article, responding to the government officials who were asking for charity to financially compensate victims (Venugopal 2008). As of 2008, no new cases of mental retardation, seizures, disability and cancer had been documented since the year 2000 by four health officers at PHCs in the affected areas (Pradyumna 2009). The exact details of the decision-making process used (including whether health impact was considered) to finalise endosulfan aerial spraying model for the cashew plantations in Kasaragod were not available to us. There is some insight on an economic analysis equating 1 day of aerial spraying to 500 worker days. There was also an underlying drive towards agricultural “modernisation” (Satheesh 2017), indicating that the push for the model came from a narrow economic perspective.

Domain expertise, either in agriculture or narrow economics, is not adequate to make a fully informed decision. This is a lesson in retrospect, but there are multiple case studies that lessons are learned late or actions are delayed for various reasons (European Environment Agency 2013). However, there is some evidence on technical recommendations in India, from as early as 1991, to keep endosulfan away from areas where there are waterbodies (CSE 2016). But it is unclear to whom these national guidelines were directed to and how they were to be implemented. Literature also provides anecdotal insights on plantation officials getting "notices" removed (these were printed to inform local people about precautions during spraying) (Satheesh 2017), which is very unfortunate but not surprising to hear. The callousness becomes even more terrifying while learning that children would come out of homes and schools during spraying operations, with the hazardous droplets falling directly on them and getting into their food plates and water. It was also discussed by local people that plantation officials would send their children home during the operations (Satheesh 2017). This points towards a crisis of professional ethics in program design and implementation.

Some of the things decision-makers could potentially have done is to consult health experts on both the toxicological and exposure aspects of aerially sprayed endosulfan. Such a consultation may not have been resource intensive and also the potential solutions may have been rather simple. For instance, these suggestions may have reduced the impacts:

- Define the proposed spray area, identify if any households or waterbodies are located in the vicinity, and direct the helicopter to avoid those areas (alternative pest control methods would need to be used in those areas).
- In addition, have a fixed schedule for the spraying, use a siren before spraying is initiated, and inform local people to strictly avoid coming outdoors during and immediately after the spraying operations.

It is likely that there are several other potential suggestions and there is a need for the public health community to encourage such action. There is a potential role of local people in monitoring any such interventions or projects. To have completely avoided any kind of health impacts, endosulfan should not have been sprayed aerially. In addition, chemical pesticides could have been avoided completely, but the technical feasibility of this can be better discussed with domain experts. In more recent times, great advances have been made in agroecological farming, and such approaches could be used even more easily in the future. Agroecological farming approaches are recommended by the UN Special Rapporteur on the Right to Food (De Schutter 2010). Company managers and government (local, state and national) officials who design and evaluate proposals should consult health professionals trained in Health Impact Assessment (HIA) to mitigate any potential health risks. The NHRC too is an important institution in the context of public health ethics and, in this case, had made several recommendations towards an endosulfan ban in India, compensation for victims and remediation and support measures (NHRC 2010). An expert panel appointed by the court in 2013 had also recommended a phasing out of the use of endosulfan in 2 years in India (HT Correspondent 2017).

The discussions here have solely focused on the issues of aerial spraying of endosulfan. Local people faced other challenges from the health determinants perspective. For instance, when the plantations were being modernised, access of local people to those previously "common" lands was stopped which affected collection of manure and fuel wood. In addition, the impact on the local ecology, with the disappearance of bees and several other creatures, also affected livelihoods (Satheesh 2017).

Health Impact Assessment as a Potentially Useful Approach in Ethical Public Health Decision-Making

The type of health and social problems faced by impacted local people in Kasaragod is very serious in nature. For instance, having children with neurodevelopmental problems would mean lifelong impact on the child and also for the caregivers. The count of only these cases was 1624 as of February 2011 (Department of Health and Family Welfare 2011). Surely this calls for concerted effort to prevent such catastrophes.

HIA for any proposed project or programme is useful for the simple reason of bringing in "health" as a consideration in the decision-making process to mitigate potential risks. Indeed in India the Environmental Impact Notification exists to protect human health and environmental health (Ministry of Environment and Forests 2006), but unfortunately it only applies to industrial projects of a particular kind (those included in the notification). The scope for this should be broadened, and, in addition, the procedure for the HIA needs to be strengthened. Currently the focus is mainly on environmental and social impact assessments, which may not be done professionally either (Pradyumna 2015). The perception of public health in the sector as well as popular imagination relates to health services (governmental hospitals) and programmes. In reality, those aspects relate more to disease than health and are associated with less than 5% of the country's GDP. It is the other 95% that determines the health of people, and so other sectors also require scrutiny from a health perspective (Birley 2011). Also, the NHRC has stated the importance of precaution and human rights as important values to consider to protect health (NHRC 2010).

The challenge is: What projects need an HIA? What should be the scale of the project? Specifically here, if a lesson should be learned from the HIA perspective, it could be that the proposed interventions (especially in plantation-type agricultural situation) that use hazardous chemicals that may potentially be exposed to local people (nonoccupational groups) should be examined for toxicity, potential routes of exposure to the local population, etc. It is important to understand that HIAs are not meant to stop projects but to identify potential health-related risks and suggest ideas to mitigate them (Birley, 2011).

Responsibility, Resources and Sustainability of Relief and Remediation Programmes

A reading of the 2015 High Court of Ernakulum judgement on the various petitions filed in the context of endosulfan in Kerala is illuminating. Several petitions have been filed by interest groups and caregivers of putatively affected persons and even counter-petitions by the workers association of the plantation corporation (The High Court of Kerala 2015). This is an unfortunate outcome of a potentially preventable situation. While the judicial system is of paramount importance, lessons from the Kasaragod experience are important to identify how better and transparent systems can be put into place to ensure that the judicial system is only the last resort. The government asked the PCK to contribute an amount of Rs. 53 crore to the relief fund, and though there was a petition against this by the workers association of the PCK (in lieu of the bad financial situation of the PCK), "considerable amounts" were donated (The High Court of Kerala 2015). This was important from the justice perspective.

Insights from key informants suggested that new cases of cancer, seizure, mental retardation and disability had been reducing as compared to before as of 2009 (Pradyumna 2009). It is possible to say that the removal of the exposure has improved health outcomes of the local people (warranting further epidemiological trend studies). However, those who have been affected will continue to live with disability, and there is a need for continued support. This was recognized by the group that met at the consultation workshop (District Panchayat, Kasaragod 2005b), and it was stated that the relief and remediation plan would need to be implemented for at least 30 years (District Panchayat, Kasaragod 2005a). The word "justice" was used in the plan document. It is unclear why specifically 30 years was stated, but such deliberation is important to ensure sustained financial allocation and support from health services.

Legal heirship has provided a challenge in the compensation of next of kin of victims who died. Also, the high court has instructed banks to not harass potential victims as long as their application for loan waiver has not been resolved (The High Court of Kerala 2015). In addition, the detailed protocols developed for identification of victims also become important as people may continue to approach the Cell for relief measures. For instance, a newspaper article from 2017 quoted a mother who was convinced that her child of 13 (born 4 years after the cessation of spraying operations) had repeated fevers and diarrhoea due to endosulfan (Sanjiv 2017). It is likely that this may not be a case of endosulfan impact, and so the protocols become important. However, it shows an important dimension of "fear" that may exist among people in this area about reproductive and child health, and mechanisms to address these emotions should be built into the remediation programme. This could potentially have several mental health impacts on many local people if ignored. Finally, it is important that other marginalised groups are not affected due to human resource and budgetary allocations towards endosulfan relief (The High Court of Kerala 2015), and so it would always be important to examine responsibilities and sources of resources. Other state-led insurance schemes have been made available for persons who need to access health services (The High Court of Kerala 2015).

Conclusions

The Kasaragod District document on the relief and remediation plan states "…such disasters should be avoided at whatever costs, in the name of humanity" (District Panchayat, Kasaragod, 2005a). As has been seen, the costs of disasters are large – both to the impacted families and the government. Cost-cutting practices eventually catch up, and someone lands up paying a heavy price. As of 2017, efforts towards a national ban on endosulfan continue to strengthen, but local people and the government should not focus only on endosulfan as the culprit. Indeed it was a constellation of poor decisions that led to the tragedy. There is a role for environmental and health considerations in decision-making about developmental and industrial projects. The government, which has the primary mandate of furthering people's interests, is in the best position to institute robust health and environmental impact assessments. This also has been explicitly discussed as part of the Sustainable Development Goals (UN 2015).

At Kasaragod, several surveys and camps have taken place. Thousands of victims have been identified, treated and compensated. Services to support healthcare, rehabilitation, vocation and education have been put in place. Unfortunately, process evaluations (if any) have not been communicated publicly. It is important for India to learn from Bhopal and Kasaragod – both towards preventing such disasters and responding to them. At the end of the day, ethical values are critical in both those levels of interventions (precaution itself being an ethical value). In addition, as may have been noticed, most of the information in this chapter has been cited from grey literature, which again points to the missed opportunities by academics to learn lessons from these health and management processes and outcomes, and write in peer-reviewed journals.

Health professionals, who were involved at every stage of the experience at Kasaragod (identifying the disaster, campaigning for action, planning and implementing relief and remediation and treating patients), have a critical role to play. Environmental health ethics can guide decision-making to protect people as long as we can systematically learn from past experiences and value health.

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Part III
Ethical Issues in Public Health Research

Chapter 6
Conducting Qualitative Research in/on Health Systems: Ethical Tensions, Confounders, and Silences

Surekha Garimella and Lakshmi K. Josyula

Abstract This chapter focuses on the authors' experiences of doing qualitative research in and on health systems and complexities. The relationship between researchers and research participants, set in a widely prevalent positivist mind set, with researchers often having to struggle to get across the message that there is not one correct answer or "complete" information that is being sought, but often subjective perspectives, are elaborated. Tensions in the design and conduct of research in health systems in India, including the difficulty in maintaining the rigour of in-depth interviews and focus group discussions sometimes, and dissonances encountered at times between certain accepted (Western) tenets of ethics, e.g. individual autonomy and privacy, in certain research and practice situations in the field are not uncommon and go to the heart of researching ethically and in a rigorous manner. In view of the fact that research is conducted into problems, and most data are of problems, dysfunction, and inequity, the researcher may often feel the disparity in the conditions of the researcher and the researched, and may frequently have to consciously disengage and recharge. We will elucidate the dynamic nature of the researcher's experience, and highlight the importance of reflexivity when using qualitative research approaches in doing health policy and systems work.

Keywords Health policy and systems research, ethics committees · Research relationships · Perceptions of roles of researchers · Informed consent · Power differentials

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Introduction and Background

There is an acceptance that research can play a vital and necessary role in understanding and strengthening public health, and health systems. While there is an overlap of definitions of health systems research, implementation research, and operational research, the broad canvas of health policy and systems research (HPSR) is increasingly being used as it recognizes the complex interconnections between health policy and systems and the political and social nature of the field (Sheikh et al. 2011). HPSR is also identified as a "transdisciplinary field" allowing it to draw from different disciplinary traditions and methodological approaches (Sheikh et al. 2014). HPSR recognizes that health systems are suffused with complex institutional, social, political, and individual relationships and practices. Qualitative research is seen as an appropriate approach to use for research questions that are not amenable to measurement in HPSR, in order to make sense of these complex relationships and practices in this field. The aims of qualitative research are normally characterised by the "what", "how", and "why" of a phenomenon (Green & Thorogood, 2004) lending themselves well to the examination and investigation of complex relationships in health systems. As Denzin and Lincoln (2000, p. 8.) note, qualitative research has "an emphasis on the qualities of entities and on processes and meaning that are not experimentally examined or measured in terms of quantity, amount, intensity and frequency". Qualitative research, therefore, is best perceived as a social process of negotiations that researchers enter into, starting from conceptualization of the issue to be researched to entering, staying in, and exiting the research site, and writing up findings.

Ethics and ethical processes are a fundamental part of qualitative research, and embody principles of beneficence, non-maleficence, protection of individuals' identity and dignity, justice, and an accurate and verifiable presentation of research findings (Baez 2002; Hennink et al. 2011; Spiezale et al. 2011). Ethical issues in qualitative research are different from those in quantitative research, and often subtle. Some of these pertain to potential ethical conflicts that exist in relation to how researchers gain access to study participants, and the failure of researchers to address ethical issues can result in their being ill-prepared for the unpredictable nature of qualitative research. Qualitative researchers mainly focus on exploring, examining, describing, and analysing people in the real world, and embedded in this are notions of power between the researchers and the participants (Posel and Ross 2015; Richards and Schwartz 2002). Since qualitative studies are mainly conducted in everyday environments, researchers are expected to be ethically literate and aware of possible ethical issues that may arise in these settings. Decisions that researchers make about ethical issues that are anticipated at the research planning stage and those that unfold during the conduct of the research are influenced by multiple factors including disciplinary norms, professional guidelines, ethical and legal regulations, and individual/team moral and ethical positions (Wiles and Boddy 2013). In an insightful reflection on researching public health and medical practices ethnographically in Nepal, Harper (2007) opines that "codes of ethical practice are prescribed in the light of judging particular events, frequently ones that have occurred in the past. They are reworked, recoded and rewritten while looking back to past digression and anticipating possible regulatory futures".

Due to the transdisciplinary nature of HPSR, there is increasing attention to the ethics in the conduct of such research, much of it focused on ethics guidelines and recommendations relevant to HPSR. Commentators opine that ethics committees as they are currently set up are not equipped to deal with ethical issues particularly relevant to HPSR (Hyder et al. 2014a). To facilitate and advance a discussion on ethical issues in health systems research, Hyder et al. (2014a) have published an initial framework. Highlighting the challenges involved in weaving together a coherent understanding of the ethics of health systems research, they make a case for the need for more empirical and conceptual research aimed at better understanding of health systems research ethics (Hyder et al. 2014b). Ethical issues that emerge in the process of conducting HPSR are not well understood, and even less understood are the influences of contexts (local, political, social, and individual) on these issues. But, as Molyneux et al. (2016) note, ethical dilemmas and challenges that emerge through the course of conducting HPSR studies are related to social relationships, often involving complex imbalances of power within research teams, between research teams and health system personnel, and between field teams and community members.

There is a vast reservoir of literature on questions of ethics in qualitative research in health, and it focuses on disciplinary guidelines, philosophical and theoretical deliberations on appropriate ethical research practice, and professional code of ethics. However, in the areas of public health and HPSR, even simple descriptive writings on experiences of ethics in research and practice are hard to come by. Reflections of ethical conundrums and conflicts that "arise in the thick of fieldwork, when researchers have to respond as human beings as much as exponents of disciplinary ethical codes, and when the unanticipated complexities of social relationships in the field throw up the latent tensions or ambiguities in the codes themselves" (Posel and Ross 2015, p. 1) are very rarely written about and shared. It is this unsettling and personally challenging aspect of ethics in practice that we hope to elaborate.

In this chapter, we share and discuss ethical issues that we faced while conducting an exploratory study on posting and transfer (P&T) policies and practices in the health sector in four Indian states, from the year 2014 to the year 2016. The objectives of this study were to investigate policymaking for postings and transfers in the government health sector, and implementation of the policies as experienced by different health system actors, and stakeholders. One of the key questions in this study was how health system actors practise and experience P&T. We used a qualitative case study approach, with in-depth interviewing, to elicit experiences related to postings and transfers among health system actors, including district health system administrators, doctors, nurses, laboratory technicians, and pharmacists. We explored their personal experiences with postings and transfers, the impact that they perceived of the postings and transfers on their professional and personal lives, and their perceptions of the rationale for postings and transfers. Specifically, we reflect on our experiences of conducting qualitative research on the health workforce in India, and share some of the ethical tensions and disconcertment that we experienced while doing the study. This is a reflexive account of selected issues related to our experiences with ethics review, seeking permission from the states to be able to conduct the study and those relating to participation and consent. This account is put together from the many discussions and conversations that we had while conducting the study, and after its completion, and is based on our individual experiences. Reflexivity can be seen as a bridge between procedural ethics and the everyday practice of qualitative research. It is closely connected to the ethical practice of research that comes to play in the real world, and an ongoing process that saturates every stage of research (Guillemin & Gillam, 2004). Being reflexive means being involved in a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants, the research context, and the interpersonal aspects of research.

Procedural Ethics: Negotiating Research Ethics Review Boards and Seeking Approval

Ethical regulation of disciplines and the production of ethics codes have varied motives, which include protecting the people being studied, preserving and promoting the image of the discipline in question, and defending it against unrealistic expectations and complaints (Hammersley and Traianou 2012). In recent decades, the centre of attention has moved to organizations where researchers work, and whom they have to deal with in carrying out research, for example, research institutes, universities, and research sites, including health systems and health service delivery sites. Institutional review boards have been set up in many organizations, and although most of them are primarily concerned with biomedical research, other research with social science approaches also come under their purview. The operation of institutional review boards is prospective in nature; therefore, these review committees hold the power to determine whether or not a research project can go ahead. For researchers like us working in the field of HPSR, and using social science approaches, this means dealing with review committees that may not be as well equipped to identify and evaluate ethical issues that may arise in this type of research (Hyder et al. 2014a). Some researchers have long been debating and raising concerns about ongoing moves towards highly regulated systems of review (Dingwall 2008; Hammersley 2009; Israel and Hay 2006). They have expressed a concern that high levels of scrutiny will foster uniform approaches to ethical issues such as anonymity and informed consent that avoid any level of risk and pose a threat to good social research, particularly for researchers who use qualitative research approaches. Other researchers focus on the importance of researchers engaging with review systems and informing the committees about methodological and ethical issues and observe that these review spaces have an educative function, helping researchers become more ethically literate (Iphofen 2011; Wiles et al. 2011).

While acknowledging the difficulties in dealing with review boards, we feel that an important and essential signpost for any research study is its submission for review of its ethics and its scientific, methodological validity. This process involves familiarising oneself with the ethics review forms, and responding to anticipated ethical issues while filling them and putting them up for review to an ethics review committee. The application includes a detailed protocol, consent forms, and research tools, and completing an application form that incorporates a discussion of the anticipated ethical issues. Adherence to the process is crucially important: without ethics approval, research is not permitted to proceed. "Ethics review is relatively unique in that it forms a kind of 'anticipatory regulation' (Hedgecoe 2012) – it assesses the likelihood of serious ethical issues arising in future if research is conducted in the way it is described in the protocols submitted for review. As such, it is based on trust that investigators will conduct research exactly as described (De Vries and Henly 2015, p. 76)".

For us, this provided an opportunity to think through and foresee ethical issues that we could face, and how we could deal with them. This, we feel, is a necessary and useful exercise, and it also indicates that the research team is ready to be examined by the ethics committee. The ethics review forms that we had to fill were more representative of ethical and methodological issues related to biomedical and public health research, and, as Hyder et al. (2014a) note, this is a common issue that HPSR researchers have to navigate. For instance, power relations, which played an important role in the ethical conduct of our research, did not feature in the review forms. Also, standard ethics approval is undertaken as a one-time event with periodic reporting and renewal, not quite addressing the dynamic, often uncertain, process of dialogue between researchers and researched that evolves throughout the research. Another aspect of this process is that all of the correspondence between the team and the ethics review panel was managed electronically. We never came face to face with the review panel and never knew the composition of the panel and the nature of the discussion when our form was reviewed. In hindsight, we feel that researchers and research teams can benefit from having access to discussions that take place among panellists reviewing the ethics application forms or being part of the discussions wherever possible. This will allow for a dialogic space to open up between researchers and review boards where both can benefit from one another.

Although ethics review boards scrutinize research proposals, the researchers are ultimately responsible for anticipating and addressing ethical issues that arise in the course of conducting research, especially those of protection of their participants. How researchers practise ethics is affected by the extent to which they are able to anticipate and address issues of distress and anxiety that may be experienced by participants; their adherence to confidentiality codes, and ability to ensure anonymisation of participants, considering that qualitative information is full of clues to identities (Richards and Schwartz 2002); their ability to avoid misrepresentation and misinterpretation of information shared by participants; and researchers' preparedness to address these issues. The main issues that we had to attend to were those of informed consent, and risk to the participants, and how we would anticipate and mitigate risks. The forms did not ask and address risks to the researchers themselves in doing the study, much less power relations among the researching team, the state bureaucracy, the health system, and prospective participants in our study. And, as we will elaborate, power relations were crucial to some of the ethical issues that we faced while conducting the study.

State Permissions and Gatekeeping Conundrums

In the build-up to obtaining permission from the states, we had started working on the protocol and settled on a research approach that was qualitative in its inquiry, and would use in-depth interviews to understand the experiences and relationships of various health system actors. Our experience in obtaining permission to conduct the study in the states was rather complicated. In some states, the authorities in charge of research approval were good-humoured and favourably disposed towards the study despite having doubts about the relevance of the work to them. These doubts arose since this was qualitative research, and they were unsure how it would generate recommendations, which was the study output that they were most interested in. Nevertheless, they gave us their approval possibly because we were from an organisation that was extensively networked with state governments, and, in fact, had other ongoing work with them. We also knew health professionals and bureaucrats through other work that we were involved in and therefore had an accommodating audience even though we were not always in accord with them about knowledge generation methodologies. In other states, despite the same scenario as stated above, we had to engage in difficult and long negotiations and bring in very senior colleagues to these negotiations to reach an agreement. A great deal of pressure was exerted on the research team to change the focus and methodology of the study. Here too, it was a case of qualitative research being seen as a poor cousin to the more influential quantitative, metric-oriented research.

A salient feature across the authorities in all states was their perception of what research is and the role that researchers should play. In the field of HPSR where researchers research the health system, cross paths and work with policymakers, differences in perceptions of what is research, and how to conduct it between researchers and policymakers can be a source of tension. This is especially so when there is a strong perception that qualitative research is simply storytelling, and therefore of little value for policymakers. Although, this tension is not insurmountable, it places additional responsibilities on the researchers to communicate the value of doing qualitative research. This can be a long drawn-out and difficult negotiation process, dealing with entrenched beliefs while allaying fears and dispelling unsubstantiated perceptions. This proved to be disconcerting, but a learning experience for us as a research team as we negotiated with very powerful authorities who included senior policymakers and health officials at the state level to address some of the concerns that they raised and, at the same time, protect and maintain the integrity of the research that we wanted to conduct. The relation between the researcher and the researched is a recurrent concern in qualitative research literature with a strong emphasis on the privileged position of the researcher vis-à-vis the researched. In the case of HPSR, it may be pertinent for researchers to reflect seriously on the issue of 'mode of entry' into health systems for doing research, and how this can influence accessibility to the researched, and researcher positionality. People vested with the power to grant permission to undertake studies are crucial and powerful gatekeepers, whose influence on the access and the integrity of the research, and the use of the information from the study, goes far beyond merely signing and issuing a letter of permission. Health systems and services have strong hierarchical bureaucratic structures that rest on top-down communication and information, and institutional privileging of statistical evidence over field-based experiences. For example, the voices and experiences of health workers and other implementers are hardly taken into account and rarely thought to constitute evidence for public health policies and programmes. This is both premised upon, and feeds into the mistaken tendency within the field of public health to dismiss such qualitative forms of enquiry as insufficiently rigorous to inform public health policy and practice (Mishra 2014; Storeng and Mishra 2014).

An issue that is intertwined with permission-seeking and the power of gatekeepers that raised ethical concerns for us was the identification of the specific geographical districts where we would conduct the study. Confidentiality, a key component of qualitative research, requires the research team to be very careful about anonymising not only the participants' names, but also any other identifiable markers. While gatekeepers in some of the states were not particular about obtaining all particulars of our study locations, in others, they wanted to know which districts we were going to select for the study. The concern and tensions that we experienced because of this were twofold. Firstly, it was about our ability to protect the identities of participants, who were frontline workers in the districts in the public health system, when the authorities already knew where we were going to conduct the study. Secondly, we were concerned about whether and how the authorities could influence what the frontline workers would share with us. We were unable to find a way out of this and had to come to terms with the fact that we could not do anything about the administrators knowing the locations of our study. The only way we could deal with this was to anonymise the details of the participants and their experiences when coding and synthesizing data.

Participants and Consent

For our study, we had to talk to a range of frontline health workers including medical officers, nurses, community health workers, pharmacists, technicians, facility level administrators, and bureaucrats located at the state level. We selected this broad range of health system actors in order to thoroughly explore policymaking and implementation experiences of posting and transfer policies in the health system. The process of recruiting participants was a multilayered experience that came with its own set of ethical dilemmas. In some states, we were given a free hand to talk to anyone we chose, whereas in others there were patent attempts to influence which individuals we could talk to. We reasoned that this could have been because of the subject matter we were researching. Postings and transfers in public health systems are sensitive subjects as they reflect on issues of accountable and transparent governance. The intent to influence the choice of participants by gatekeepers was possibly based on the expectation that the individuals the gatekeepers recommended to us would give positive accounts of their experiences.

A particular dilemma we faced in relation to this is that there are specific, limited numbers of posts in some of our participant categories in the sites selected for the study, and therefore we had to interview some individuals even though we did not expect them to be sufficiently expressive and informative about their experiences. The onus then fell on us to be more vigilant when conducting the interviews. Individuals' decisions to participate in research may not always be in line with the notion of voluntariness, which is a key principle of research ethics. This principle advocates that individuals should be able to decide for themselves, with as little influence as possible by others, whether to participate or not. But, in hierarchical organizational structures such as in health systems, decisions to participate may not be entirely voluntary, and individuals may volunteer to participate because they do not want to go against their superiors. This issue is most critical to the least powerful in the hierarchy.

Another factor that may influence participation is the presence of the researchers themselves. When doing field work in health systems, the researchers are a visible and available entity because of their physical presence and can influence the choice to participate. In some states, we needed the help of individuals to help us with identifying and setting up interviews with participants. These were mid-level executives, trusted by the administrators and frontline workers alike, people well respected in the system, who helped us gain access to participants and probably also influenced the decisions of individuals to participate in the study. We tried to deal with this by having an honest dialogue with the gatekeepers so that the participant selection process was transparent and as open as possible.

Following the identification of prospective participants, informed consent is sought before interviews can take place. Informed consent is a core concept in ethical research practice, and a fundamental principle underpinning guidelines for researchers. In its most basic interpretation, it involves providing clear and comprehensible information about what participating in the research project will involve and giving prospective participants the opportunity to decide whether or not they want to participate. Clarity is provided on the following: what the research is about, and why it is being conducted; who is funding the study; what participating in the research will involve, including potential risks and benefits; what efforts will be made to protect participants' identities, and how confidentiality and anonymity will be managed by the research team; and how the results of the study will be used. Of vital importance is the researcher's duty to clarify that the prospective participant is not obliged to take part in the study and, once having consented to participation, can withdraw from the study at any point, with no penalty. Although this appears clear and straightforward, in practice, researchers have to deal with a range of factors when managing issues of informed consent. For example, we contemplated how much choice the participants actually had to refuse to participate in our study, since we went in with officially approved letters stating that we had been given permission to talk to people. No one whom we approached for participation refused to participate in our study. Some of the interviewees were open, expressive, and voluble. Some others appeared hesitant to discuss their posting and transfer experiences, and asked for confirmation during the interviews that their identities would indeed be kept confidential. Some of our participants expressed apprehension that their hitherto smooth record of no hierarchical interpersonal tensions in the workplace might be threatened by our discussions of the sensitive topic of posting and transfer. These observations led to our feeling unsure of the role that informed consent actually played in individuals' accepting to be part of the study.

An observation that has stayed with us in relation to the conduct of interviews in HPSR is that the sanctity of the in-depth interview was sometimes violated by hierarchically superior health system actors. For instance, a health system administrator, who introduced the researchers to a mid-level or frontline worker, sometimes entered the interview room in the course of the interview and participated in the rest of the discussion, patently affecting the candour of the interviewee and rendering some of the "interview" not truly fit to be analysed as an interview. We recognized that this intrusion, which amounts to gate-crashing, was not executed with any damaging intent; rather the gate-crashers were clearly exerting themselves to help us. Often interviewees or gatekeepers would invite a colleague into the interview to provide "better" and "correct" information on the matters that we were studying, not quite grasping the fact that we were exploring people's individual perceptions, experiences, and interpretations, and not aiming to get at any particular objective truth on postings and transfers. A clear understanding of the goals of research, as distinct from fact-gathering in implementation and evaluation of health system work, was lacking in the majority of the health system actors whom we interacted with. Our attempts to explain that we were trying to understand the perceptions and experiences of people, and not gather statistics and metrics, seemed sometimes to do our image a disservice, indicating that we were engaging in an investigation with neither concrete variables nor proximate benefits to the health system.

Many frontline workers, especially persons with low autonomy, took the presence of researchers asking unusual questions – such as those about professional, interpersonal, and individual experiences, opinions and philosophies of work, and suggestions for improvement – as an opportunity to express their perceptions and aspirations fully and freely. They described their gratification with the policies and practices that promoted their wellbeing, and spoke of their angst at the policies and practices that they felt were insensitive to their needs and disenfranchised them. In our conversations with them, we frequently found that they were looking to us to communicate their case to the powers-that-be, and hoping for our advocacy to strengthen their representations to the authorities. This additional expectation of the role of advocate or broker placed on the researchers tended to sit uncomfortably on us, in our inner tussle between the objectivity and reflexivity required of a researcher and the empathy that we could not help feeling as we interacted with, and understood the experiences of the interviewees.

Informed consent in research operationalises autonomy. It is commonly understood as the right of individuals to make their own choices, and is a fundamental value in Western societies. Our experience of researching in health systems suggests that the hierarchical structuring of the health system is a very alive and palpable context that influences the right and choices of participants in their decision-making to consent or not, as we have elaborated above. This issue needs more discussion and thinking through among researchers in HPSR.

The Researcher-Researched Relationship

There is rich and wide-ranging literature on the relationships between the researcher and the researched in qualitative health research, social sciences, and feminist research. A recurrent concern in this literature relates to what is seen as a fundamental and inherent imbalance in this relationship, specifically the privileged position of the researcher vis-à-vis the researched. The ethical issues associated with this power imbalance are elaborated upon, with a focus on predetermined asymmetric roles. There is also an emphasis that all qualitative traditions have a common epistemological ground which is the researchers' determination to minimize the disparity in this relationship (Karnieli-Miller et al. 2009). While we acknowledge the existence of an imbalance, in relation to our study, we have had to question whether the researcher is always located in a privileged and superior position in relation to the participants. The range of participants included in our study meant that we were both "studying up" (the bureaucrats, administrators, and medical officers who are the more privileged in the health system) and "studying down" (nurses, community health workers, pharmacists, technicians, and other allied personnel who are the less privileged in the health system).

Nader (1969/1972) launched the dichotomy of studying up/studying down pertaining to researcher positionality, holding that studying up contributes in vital ways to an understanding of the processes by which power and responsibility are exercised. Beyond informing our understanding of patterns of distribution, value, and power, the researcher who is "studying up" may experience moving into a research field of less "control" or "power," so the approach calls for new reflections on the issues of access, methodology, attitudes, and ethics (Nader 1969/1972, p. 301; Pfeiffer and Nichter 2008). In simple terms "This refers to the study of those in power (policy makers and influential stakeholders), those subjected to the directives of those in power (parties charged with implementing programmes downstream as well as programme recipients), and those who are motivated to frame, fund, and publicise research for a myriad of purposes" (Ahlin et al. 2016).

We wanted to study up to understand how power and responsibility are exercised in influencing the policy and implementation of postings and transfers. Studying down was also important because we wanted to bring out voices that are usually not given due importance in health systems. While studying up and studying down, we experienced fluidity in relation to how we found ourselves positioned in relation to the participants. Studying up did not always put us in a vulnerable position, and studying down did not always put us in a superior position. With some participants, there was a clear delineation of power that we held, whereas with others it was very fluid and changed during the course of the interviews. Sometimes powerful participants exhibited vulnerability when detailing their own personal experiences of transfers, while the less privileged in the system positioned themselves in a superior space in relation to us by clearly choosing to be very generic in their accounts and stonewalling any attempts to elicit nuanced narratives. Given our experience, we believe that a more nuanced and fluid understanding of the researcher-researched relationship is needed. Accepting that power exercised in these relations is dynamic and complex will allow room for discussions around how the researched are perceived, and more discursive accounts of the modalities of power associated within this relationship will emerge, to be shared (Smith 2006).

In view of the fact that research is often conducted into problems, and most data are of problems, dysfunction, and inequity, the researcher may often feel the disparity in the conditions of the researcher and the researched, highlighting the predicament of the participants further. We found ourselves in this situation time and again distressed at the circumstances that some of our interviewees lived and worked in, particularly those of our participants who experienced an intersection of multiple disadvantages, such as of gender, social status, cadre, and type of employment contract. We had to consciously disengage after the interviews and recharge, as we traversed, in our minds, waves of activism, advocacy, optimism, problem-solving, and disenchantment. In addition, because we were researching a sensitive topic with considerable social, organizational, and personal ramifications, we sometimes came up against clashes of our own ideologies with those of our interviewees. In such situations, we had to proceed with composure and maintain our reflexivity in the manner and extent of data elicitation, as well as in the interpretation of information. For instance, we conducted some interviews with persons trained in the same or allied academic discipline as a member of the research team, and this commonality facilitated greater openness and understanding as the interview progressed. In some interviews, on the other hand, the interviewee expressed views adverse to the academic disciplines, or personal creeds, of the research team members, engendering a conflict of values, which while we did not articulate in the interview, nonetheless struggled with internally.

Concluding Thoughts and Reflections

In this chapter, we have attempted to share our experience of conducting HPSR using a qualitative research approach in a study that focused on experiences of health workers, administrators, and bureaucrats, in relation to posting and transfers of personnel in the health system, and some of the attendant ethical issues that we encountered. We have shared descriptive accounts of our experience in relation to ethics review committees, particularly their unfamiliarity with the field of HPSR, leading to their being ill-equipped to foresee and deal with ethical issues peculiar to HPSR; seeking permission from states to conduct the study; ethical issues that arose in relation to recruiting participants and obtaining consent; and the fluid and dynamic nature of power in the researcher-researched relationship. We focussed on these issues to highlight the fact that relational concerns across the research process are often critical in determining the ethical questions that researchers have to engage with and influence the practice of ethics.

There are calls in the area of HPSR for embedding research in the real world of policy, practice, and implementation in order to strengthen health systems (Ghaffar et al. 2017). This is advocated on the basis that research conducted in partnership with policymakers and implementers in health systems, with attention to context-specific factors, will have greater relevance for the system. While this is ideal, in the real world of research, this thought and practice are not always universal. Alongside advocacy for context-sensitive research approaches in HPSR, there is ongoing advocacy for identifying and conceptualising ethics issues and a push towards building suitable oversight mechanisms of HPSR (Hyder et al. 2014a, b). From our experience on interactions with ethics review committees, we strongly feel the need for a more dialogic and open-ended interaction between researchers and these committees, researchers and health systems policymakers and implementers, as well as among researchers on ethical issues in a transdisciplinary field such as HPSR.

Conversations around these issues have been initiated through the thematic working group (TWG) on ethics in HPSR[1,2] under Health Systems Global (HSG), an organization that is advocating the field of HPSR. Research in Gender and Ethics (RinGs) is another network which focuses on gender and ethics analysis in health systems (http://resyst.lshtm.ac.uk/resources/ethics-health-systems-research-selected-guidelines-and-studies).[3] In addition, as HPSR researchers we are responsible for inculcating ethical mindfulness in our approaches. The relational issues that we have raised are accorded greater emphasis in social sciences and feminist research ethics, and a deeper engagement with this literature would strengthen a move towards more nuanced ethics of practice in HPSR.

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[1] http://www.healthsystemsglobal.org/twg-group/9/Ethics-of-Health-Systems-Research/

[2] This working group seeks to build awareness of and interest in the wide range of ethics guidance and literature that is potentially relevant to HSG members; identify ethical dilemmas experienced over the course of funding, planning, conducting, disseminating, and reviewing diverse forms of HPSR; and share ideas on how relevant ethical theories and principles might be applied to support practice and contribute to guidance for HPSR stakeholders and to contribute scholarly work to the global discourse on health systems ethics and HPSR ethics, especially in LMIC.

[3] http://resyst.lshtm.ac.uk/resources/ethics-health-systems-research-selected-guidelines-and-studies

System, Strategic Health Partnership for Universal Health Coverage (Governance and Regulation)". We are grateful to the research participants, who stimulated many of these perspectives, as well as to the field assistants with whom we had several conversations that led to the insights that we have presented here. We would like to acknowledge Gupteswar Patel, Bhaskar Purohit, and Kabir Sheikh from the research team conducting this study. We appreciate the collegiality in the Health Governance Hub, which nurtured our meditations on ethics in the conduct of HPSR. The reflections shared in this chapter are personal and our own.

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Chapter 7

Data Ethics in Epidemiology: Autonomy, Privacy, Confidentiality and Justice

Vijayaprasad Gopichandran and Varalakshmi Elango

Abstract Epidemiology is an essential tool of public health, which largely relies on collection, collation, analysis and interpretation of data and actions based on the information gleaned from the data. Such data-intensive processes lead to unique ethical issues relating to autonomy of the data generator, privacy, confidentiality and justice. In this chapter, we attempt to describe the ethical issues in data handling in epidemiology using two examples, public health surveillance and Big Data analytics in digital epidemiology. One of the unique ethical issues that arises in public health surveillance is the difficulty in operationalizing autonomy, as any individual refusing to share surveillance data will compromise the effectiveness of the surveillance. The need to balance the benefits of health security with the risks of infringement into individual privacy and confidentiality lies as the undercurrent of the ethics of public health surveillance. Big Data analytics is becoming increasingly popular in public health. The rich variety of the data, while offering chances of multilevel, multivariate analysis of disease models, also raises concern of biases in data collection due to huge variations in the sources of the data. The high velocity of the data also throws open opportunities for rapid analysis and interventions to improve population health. The power of Big Data analytics needs to be harnessed with the important ethical principles of public health in mind.

Keywords Big Data · Digital epidemiology · Electronic health records · Privacy · Confidentiality · Data protection

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Introduction

Large-scale population-based epidemiological research, epidemiological data collection, epidemiological surveillance and such activities which are data intensive are an integral part of public health practice. While such population-based data collection is a powerful tool for understanding the health status, disease epidemiology, resource availability and health needs of a population, access to such important health-related data opens up several ethical issues. Firstly, access to large datasets of personal and identifiable health information from populations can impinge on individual privacy and confidentiality of data. It raises fundamental ethical questions such as: Who owns the data, who can access the data, and how should the data be protected? Secondly, collection of such data, as part of routine public health activities, often is mandated by the public health authority of the state, and there is often little autonomy or choice for the individual. Moreover, for epidemiological data to be most useful, it should be comprehensive. This means that the data from all people in the population should be available for analysis. This leaves little choice for individuals to opt out of providing their data. Thirdly, whether such data collected under the mandate of public health activity can or is being used for other research purposes raises an important ethical concern. Therefore, when the state has ethical responsibility in the spirit of stewardship to ensure the health security of a country, it is difficult to prioritize autonomy of individuals in contributing to epidemiological data. These ethical considerations and dilemmas make ethics of public health and epidemiological research unique.

The first part of this chapter will address an important epidemiological activity, namely, public health surveillance, and illustrate with examples the key ethical considerations in this activity in the Indian context. The second part will address a more recent trend in epidemiological research, namely, digital epidemiology and Big Data analytics. Using these important public health activities as examples, the chapter will explore issues of data privacy, confidentiality, justice and equity in epidemiological research.

Public Health Surveillance as an Epidemiological Activity

Public health surveillance (PHS) is the close scrutiny of health status and factors that could impact the health of the population. The 600-year-old idea of surveillance was refined and described in its modern form by William Farr. The World Health Organization (WHO) defines public health surveillance as “the continuous, systematic collection, collation, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice” (Abraham et al. 2017). Public health surveillance is conducted for a variety of purposes; to name a few, it allows to monitor disease trends, identify the onset of epidemics, observe changes in disease-causing agents like influenza or “drug-resistant bacteria", prioritize diseases that require intervention, assess the impact of intervention and measure the progress (Brownstein et al. 2009). In 2007, 196 member states signed up to the International Health Regulations (IHR) 2005, and in this context, surveillance serves as a key early warning system for identifying public health emergencies of international concern (Buse and Hawkes 2015). Being signatories to and having the obligation to comply with the IHR, most low- and middle-income countries are establishing their own public health surveillance systems with or without support from external donors. As an epidemiological activity, PHS is performed through several modalities, namely, passive disease reporting by health workers, health-care facilities and laboratories, sentinel surveillance from specific sites covering targeted cohorts, secondary non-surveillance data from health management information systems, demographic and health surveys and health insurance database and digital data sources such as social media, Internet web services and e-commerce websites (Dean 1999). PHS, which has become an essential public health activity, has several important ethical considerations. The following paragraphs will describe the ethical considerations in PHS.

Ethical Considerations in Public Health Surveillance

Autonomy, Privacy and Confidentiality

Autonomy has been a highly contentious ethical issue in PHS. Informed consent has been the hallmark of upholding the principle of autonomy of people when they participate in research activities. Obtaining informed consent from the people for purpose of using their data for PHS is difficult to operationalize given the massive numbers of people usually contributing their health data to the PHS. Moreover, when large numbers of people refuse to share their data for PHS, it may compromise the quality of the PHS. Sometimes blood, tissues and fluids are collected as part of routine surveillance, and the participants often give their samples with a perception that it is part of health-care service provision. In low- and middle-income country settings, with low literacy levels, the people sharing their data and samples often do not know that a surveillance is ongoing. The autonomy of the person contributing the data is compromised for the sake of the larger good of the community. Another matter of particular concern is the use of such data and samples for research purposes other than surveillance. This is because the participants who contributed data did not provide the data or samples for the sake of research to begin with. Their understanding, if any, was that it was part of service provision. In case of unlinked anonymous testing (UAT) for HIV, the situation is worse, as the patients do not even get to know their HIV status at the end of the surveillance testing activity. These circumstances place PHS at a very precarious position when it comes to respecting the participants' autonomy.

PHS, as an essential public health activity, entails the collection of personal and private medical information from people in order to serve a larger common good. As mentioned previously, sometimes the people are not even aware that their private health-related information is collected for purpose of surveillance. They are also often unaware that this identifiable private information may be accessible to researchers and public health officers for purpose of interventions. Therefore, ethical safeguards to the individual's autonomy, privacy and confidentiality of sensitive medical information are essential while conducting PHS. It is also important to assess if the extent of infringement into the privacy of an individual is proportional to the common good that is achieved by the surveillance.

A historical anecdote in the 1980s at the time of the beginning of the HIV epidemic in India provides deep insights into the ethics of PHS. Routine sero-surveillance of women involved in sex work was established at that time. One of the authors of this chapter was working in a medical college microbiology department at that time, and she was witness to the events that are described below. The women involved in sex work were brought from their respective homes and paraded in the microbiology laboratory of the big medical college without any concern for their privacy. Their blood samples were drawn and tested to identify HIV serology. The author has witnessed several such instances of women being tested in medical college departments without any privacy safeguards. The fear of HIV and the looming threat of a smouldering pandemic were so great that issues of autonomy, privacy, and confidentiality took a secondary priority. Though the risk of HIV was high and need for the surveillance immediate, it also warranted acute attention to ethical safeguard measures to protect the women's privacy and confidentiality, which were violated. Therefore, in order to protect these ethical principles, there is a need for rigorous ethical scrutiny of PHS.

Responsiveness of the PHS to Local Health Needs

As seen previously PHS aims to produce a common good which ensures health security to the community. Therefore, such an activity has to be responsive to the local needs of the community. India is currently facing a dual burden of disease including both communicable and non-communicable diseases (Fidler and Gostin 2006). The PHS should target both these types of diseases. Often, donor-driven vertical surveillance systems in low- and middle-income countries cater to the priority needs of the donor country and global priorities. A typical example for this was the Millennium Development Goals (MDG); three major diseases including HIV/AIDS, tuberculosis and malaria had been given top priority (Government of India 2017). There are several other diseases like dengue, leprosy and leptospirosis which were not prioritized for surveillance (Hartley 2014). Now the Sustainable Development Goals (SDG) target a broader spectrum of diseases such as AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. While this is an important consideration at the macro-policy level, there are important issues at the micro level as well. One such issue is human resources for surveillance.

Human Resources for Surveillance and Conflicts of Interest

The Integrated Disease Surveillance Program (IDSP) utilizes the services of the village-level frontline workers such as auxiliary nurse midwives (ANM), multipurpose health workers and Anganwadi workers to report cases of illnesses from the community. These workers are often overburdened[1], and this may compromise the quality of PHS. There may be conflicts of interest of the community health worker as she is the same person who is providing preventive services and hence reporting of illness may reflect negatively on her quality of work. The following example, witnessed by one of the authors in her experience, illustrates the ethical importance of proper utilization of human resources for surveillance. In the early 1990s, a paediatrician working in a government hospital in Tamil Nadu, India, was given a punitive memorandum for not reporting a child with acute flaccid paralysis (AFP). It was a period when incidence of polio was high in India and the National Polio Surveillance Program (NPSP) was actively tracking cases of AFP. All paediatricians were mandated to report cases of AFP that they saw in their practice. Unfortunately, information about the activities of NPSP and modalities of surveillance were not widely disseminated among the paediatricians in the country. While paediatricians from cities and towns had the luxury of exposure to the information, those practicing in rural and remote areas had no way of knowing the details of the surveillance. Like in most instances, surveillance inputs were maximum from government health facilities, and private health facilities remained oblivious of the surveillance activity. This example highlights the importance of proper engagement with all stakeholders in the surveillance for the surveillance to be appropriate. The state has a responsibility to create due processes and systems to ensure proper conduct of surveillance. Punitive action on the surveillance staff in the absence of appropriate supportive supervision can impair the morale of the staff and thus compromise the quality of the surveillance. Apart from respect to individuals and procedural ethics, justice considerations are very important in PHS.

Justice Considerations in PHS

In one of the most backward districts of Tamil Nadu in terms of health indicators, in the early 2000s, there were a number of cases of fever with rash among children below 5 years, including several deaths, due to a mysterious febrile illness. The

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[1] The auxiliary nurse midwife is the backbone of the public health function in India. Her primary responsibilities include registering pregnancies, issuing antenatal card, performing antenatal visits and visiting the mother at her home, dispensing iron and folic acid tablets, giving her tetanus toxoid injections during pregnancy and motivating her for institutional delivery. She does home visits immediately after delivery, initiates breastfeeding, monitors the baby, immunizes the children till 2 years of age, advises on contraception and provides contraceptive methods to the eligible couple. In addition, she also maintains meticulous records of all the maternal and child health activities in numerous registers. She is also often required to perform additional duties like communicable and non-communicable disease prevention and control activities. She is in charge of a total population of 5000–10,000.

press had captured this information and had created a kind of panic. Further analysis had revealed that most of the cases of this mysterious febrile illness were reported from the Dalit (scheduled caste) colonies of the villages. Further investigation of the outbreaks revealed that it was a measles outbreak. The village health worker in this area had been informed of this illness very early on but failed to investigate or report it. Inquiries revealed that the health workers did not intervene fearing punitive action. Further investigation into the situation also revealed a gross neglect of health services including immunization, antenatal care, care of children under 5 years and family planning services in the Dalit colonies. This case study brought to the forefront certain deep-rooted social justice issues in public health surveillance. The fact that a surveillance system was present but did not capture the early warning signals is evident. Firstly, there was a gross failure of the surveillance machinery due to failure of the health worker to report the illness among the children in the Dalit colonies due to her role conflict as health provider and as surveillance reporter. Moreover, the inadequate surveillance was evident in the Dalit community, as the health worker had systematically neglected all activities spanning from basic health care to surveillance in the community. Establishment of a good PHS must ensure that all members of the community are reached by the surveillance and the common good that is accrued due to the surveillance is distributed to all the members equitably.

The other issue closely related to justice is the availability of necessary standards of care in the community where surveillance is carried out. In the Dalit community described above, marginalization based on caste had systematically deprived the community from required standards of care. Therefore, establishing a robust surveillance system in this area would be unfair as there is a lack of concomitant provisions of care for those identified with illness. In parallel to development of a PHS, there should be strengthening of health services in the community (Heymann 1998). Having a robust surveillance system in the marginalized community, without adequate standard of care, would unevenly distribute the burdens and benefits of the PHS activity. While the villagers belonging to the other castes will benefit from the surveillance, the Dalit community will bear the burden of loss of autonomy, privacy and confidentiality without any actual benefit.

One of the challenges has been the limited availability of guidelines for ethics in public health surveillance. Ethics of public health is a recent development in the global public health arena. The fine line of differentiation between public health research and action further confounds the understanding of ethics of public health. There are several important ethical guidance documents for health research including the Declaration of Helsinki, Council for International Organizations of Medical Sciences (CIOMS) and International Council for Harmonization-Good Clinical Practices (ICH-GCP) (Hoerbst and Ammenwerth 2010; Idänpäaumln-Heikkilä 1994). The CIOMS also brought out the ethical guidance for epidemiological research, but PHS, which lies in the interface between research and public health practice, falls within the gaps in the ethical guidance. Most recently WHO has published a guideline on the ethical issues in public health surveillance which will serve as a useful tool for member states for setting up public health surveillance systems and the ethical oversight mechanisms (Jetten and Sharon 2016).

Ethical Oversight in Public Health Surveillance

The most contentious issue is whether PHS is research or not. This has been the subject of extensive debate in literature. It is difficult to draw a definitive line between surveillance and research. Like research, surveillance involves the collection of data from individuals or community, the analysis of which provides evidence for decision-making. In this sense, it poses risks similar to that of research. And if surveillance poses risk to all those individuals, patients or communities who have contributed their data, there is a need for ethical oversight to review if these risks justify the common good and how these risks could possibly be mitigated.

As PHS is not clearly considered a research activity, public health practitioners do not include it in regular research ethics scrutiny. In the absence of alternate review mechanisms, ethical oversight is often not performed. Therefore, there is a need for ethical review systems for PHS. In this regard, the Public Health Ontario has formulated a framework of ten guiding questions that allow for ethical reflection of all public health evaluative activities. These questions guide the practitioner to assess the following ethical considerations:

- The stated objectives and how the intervention proposes to address the objectives
- Whether the proposed intervention is capable of achieving the objectives
- A clear understanding of who the beneficiaries of the intervention are
- A clear understanding of the burdens and benefits of the intervention and the specific groups of people who will enjoy the benefits and suffer the burdens
- Justification for the potential burdens and harms in light of the benefits of the intervention
- Fair and impartial selection of participants in the intervention
- Considerations of individual autonomy in terms of informed consent – feasibility, appropriateness and sufficiency
- Considerations of community engagement
- Social justice considerations
- Potential long-term consequences

This is a valuable tool for those setting up and reviewing the merits and ethical considerations of a public health surveillance (Kintu et al. 2005).

Whether there should be a separate model of an Ethical Review Committee for public health interventions and activities in India is a matter for discussion. Building the capacity of existing Ethical Review Committees in the country to review public health research and surveillance protocols may be more feasible and efficient in the immediate future.

Another challenge is the fact that LMICs, where the need for public health surveillance is the highest, do not always have the capacity even for ethical review of research protocols. This calls for capacity building of ethical committee members and public health practitioners in being able to better understand the ethical issues and apply the nuances of ethical principles in the context of public health surveillance.

In a country like India, the Indian Council of Medical Research and the Department of Health Research, Government of India, after due consultations with the various stakeholders, should institute appropriate ethical oversight mechanisms for public health evaluative activities in general and public health surveillance in particular. Closely related to PHS and oftentimes contributing to PHS as a data source are digital epidemiology and Big Data. The next section discusses the ethical nuances in digital epidemiology and Big Data analytics.

Digital Epidemiology and Big Data Analytics

Traditional methods of epidemiological research are fast being replaced by modern technology. In the past, epidemiology was practiced dominantly by primary data collection. Researchers in the field collected health-related data and analysed them to discern patterns in terms of burden, distribution in time, space, person and determinants of diseases. The advent of computers and computer-assisted statistical data analysis marked a transformation in the practice of epidemiology. More complex data could be handled and analysed and led to better understanding of patterns of disease. In recent years, there is a near-ubiquitous proliferation of Internet access in most parts of the world. A large segment of the population also has access to mobile phones. The advent of the Internet and ease of data access has heralded a new age of epidemiology, the era of digital epidemiology (Lee et al. 2012).

Digital epidemiology is the use of digital electronic devices, Internet connectivity network and cloud computing capacity for studying disease burden, disease patterns and determinants (Liang et al. 2014). Application of digital technology for epidemiology has provided several advantages. Firstly, it has made data collection and handling easier, faster and more accurate. Software like the Epi Info, developed and distributed by Centres for Disease Control and Prevention, Atlanta, USA, have been used for many years now effectively to investigate outbreaks and conduct epidemiological investigations (Mahapatra 2017). Newer versions of the software have been developed as Android application which can be accessed through mobile phones, tablets and other hand-held devices, thus making data collection and handling very easy. In addition, health systems are establishing health management information systems (HMIS) which help in monitoring, learning and evaluation of public health programs (Ministry of Health & Family Welfare 2016). The Mother and Child Health Tracking System (MCTS) is one such database for tracking the health and wellbeing of mothers and children in the community from pregnancy up to 6 years of age of the child. Community health workers in many settings are using mobile applications and hand-held devices to collect and update health management information system data for effective public health-care delivery. Hospitals are also developing their own electronic health records of individual patients, which help in maintaining digital records of all patient encounters, thus making documentation and access to patient data easier for the treating physicians (Ministry of Law and Justice (Legislative Department) 2016). The availability of such immense volume of health data in the digital format has led to improvements in epidemiological research capacity. Health-related information from these variety of data sources serve as potential epidemiological data. They help in early and real-time detection of outbreaks of diseases, understand patterns of diseases and even study associations between diseases and risk factors.

Another emerging area of digital epidemiological data is health-related behaviour data from social media. Social media platforms like Facebook, Twitter, etc. have huge volumes of data on health-related behaviours. These can provide information on behavioural linkages with health (MMWR 2012; Noble et al. 2012). In the era of cashless and digital commerce, purchasing practices also leave a whole lot of digital data trails. Thus, purchasing behaviours which have a direct implication on health care also can be obtained from this digital data. For example, Twitter feeds on influenza have been used in assessing patterns of seasonal influenza outbreaks (Public Health Ontario 2012). Similarly, data on purchase of sugary carbonated beverages and high-calorie foods can provide information on non-communicable disease risk in communities.

With advent of Global Positioning System and geospatial mapping, another potential area of digital data is easily available for epidemiological analysis (Salathé et al. 2012). With a large majority of people having mobile phones with geographical positioning capacity, disease clustering, geographical patterns in disease outbreaks, etc. can be easily tracked. Satellites are also constantly monitoring the weather and climatic conditions as well as the environmental conditions such as air and water quality. These data are also available in the digital format for epidemiological studies.

The combination of all these types of data can assist understanding of complex disease patterns and trends. In this context, it is important to understand what Big Data is. Big Data can be defined as large pools of complex data from multiple sources that can be collected, communicated, collated, stored and analysed (Salerno et al. 2017). The characteristic features of Big Data are that it is of high volume, produced at high velocity, in a huge variety of formats, with doubtful veracity and huge variability in the magnitude of data with time. In other words, Big Data is enormous and very messy (Sarasohn-Kahn 2008). The fact that it is voluminous, of huge variety and nearly real time in generation is of immense advantage in epidemiology as it helps discern disease patterns in a timely and accurate manner. However, the fact that it can be unmanageable because of its volume and variety and of doubtful veracity can limit its utility (Signorini et al. 2011). Digital epidemiology derives very strongly from Big Data analytic capacity as described above. There is immense potential for linkage of various databases. The data from electronic health records and health management information system can provide disease burden information. This can be effectively linked with the behavioural data from social media, environmental and geospatial data and interesting patterns identified. The data can be stored and computed in digital clouds and easily retrieved from the cloud. This further eases the process of Big Data analytics and provides a huge potential for application in epidemiology (Unique Identification Authority of India 2016).

The future of epidemiology may be digital and Big Data analytics. Traditional epidemiological research using data collection, storage and analysis may be slowly phased out over the years, as almost all human activity now leaves a digital trail. In this context, it is important to rearticulate the key ethical concerns in epidemiological research. The following section of the chapter will highlight the ethical concerns in digital epidemiology and Big Data analytics.

Stakeholders in Digital Epidemiology and Big Data Analytics

There are multiple stakeholders in the process of digital epidemiology and Big Data analytics. It is important to identify these stakeholders in order to discuss the ethical implications of digital epidemiology for these stakeholders. In epidemiological Big Data, there are three key stakeholders, namely:

1. Data collectors – these include the public health system who collect data as part of their program management, monitoring and evaluation, the hospital administrators who collect data for maintaining patient records and management of the hospital functioning and non-health players such as social media platforms and digital commerce platforms like e-commerce providers.
2. Data generators – these include the people who generate these data through utilization of health services, utilization of treatment facilities, e-commerce, social media posts and interactions and even the mere process of using search engines for looking at diseases and disease treatment.
3. Data users – these include the health system, epidemiologists, health-care providers, researchers and policy-makers who use these data for making epidemiological inferences and generate evidence for policy-making.

There are important ethical implications for each of these stakeholders. Firstly, the data collectors, specifically the non-health collectors of data such as social media platforms and commercial websites, have access to sensitive information related to people’s health and behaviours. This has misuse potential such as commercial sale of database for marketing purposes and release of sensitive private information of a person without their knowledge. Further, such access to sensitive data gives an unbalanced power of information to these data collectors. Secondly, the data generators are often completely unaware of the potential use of the digital data that they generate and often are rendered vulnerable by the digital transparency of their private information. Thirdly, there is often inequity in which type of data user gains access to digital data, with the corporate users having easier access to Big Data compared to the government public health users. Ethical analysis of digital epidemiology and Big Data analytics needs to consider all these stakeholders and the ethical implications for each of them (Signorini et al. 2011). These issues are described in detail in the following paragraphs.

Important ethical considerations in Digital Epidemiology and Big Data Analytics

Some of the important ethical considerations in use of digital epidemiology and Big Data analytics are concerns regarding privacy of sensitive information that is generated by people, especially in the non-health digital space, which is being used for epidemiological studies, doubtful veracity of the Big Data due to huge volume of "noise" in the data leading to harm, use of people's data for epidemiological research often without individual consent and concerns regarding equity in access to Big Data and its benefits.

Concerns of Privacy

Sensitive private information may be accessible to the epidemiologist for Big Data analysis without any restrictions. Data on sexual orientation, which may be observed from social media and other non-health-related digital domains, can seriously violate an individual's privacy, sometimes incriminating them to prosecution, especially in India where homosexual orientation is criminalized. This is particularly problematic because the data generator often does not know the potential for the use of their data for health-related analysis. The IP address of the individual can be exactly traced back to them, and it may expose them to risks of loss of privacy. Even if the digital data is anonymized for purposes of epidemiological research, it may be difficult to strip the data of geospatial identification or group identity. This may lead to loss of "common privacy" or "group privacy", which is the privacy of a group of people sharing a common set of values, behaviours and practices (Unique Identification Authority of India 2016; Vayena et al. 2015). For example, digital patterns of purchase of medical products online may disclose the privacy of individuals or of groups of individuals. It may lead to stigmatization of individuals or groups based on the diseases for which they purchase the drugs.

Doubtful Veracity of Data

Big Data, as we saw before, comes from a wide variety of sources. Many of these sources are not scientifically robust sources of information. For example, multiple visits to a particular health-related website may be completely unrelated to the health condition that is covered in the website and may be just unintended visits. This huge volume of "noise" in Big Data renders the data unreliable and sometimes erroneous. It is important to have strong analysis protocols which are robust enough to identify noise. Big Data analysis has sometimes led to wrong identification of outbreaks. For example, the Google Flu Trends (GFT), a web service that claimed to predict influenza activity in about 25 countries worldwide, used the health tracking behaviours of the search engine users and queries related to influenza to predict the activity of the illness. In the period between 2011 and 2013, this web service consistently overestimated flu activity in the United States. Following the identification of this problem of accuracy, the GFT is no longer publishing current influenza estimates. This is a potential harm in use of digital epidemiology and Big Data analysis. Unless the Big Data analysis capacity is substantially increased, use of digital epidemiology can lead to harms because of doubtful data veracity (Unique Identification Authority of India 2016; Vayena et al. 2015).

Informed Consent

One of the important pillars of research ethics is informed consent. Obtaining a fully informed consent from the participants in the research for collection, storage, analysis and dissemination of their data is an essential prerequisite which demonstrates the respect for autonomy of the individual. Each person who provides their data for epidemiological research should have the right over their information and should voluntarily decide to participate and share their data. However, digital epidemiology often uses data for which the data generators have not provided consent for research use. This is in violation of the principle of autonomy of the generators of data, who are mostly unaware of their data being used in epidemiological research. Though most digital platforms take a bracket consent that is packaged in several words of small print, data generators pay little attention to the fact that the digital data trail can be potentially used for research and could be traced back to them. Such compromise of individual autonomy should be carefully balanced with ethical protection mechanisms such as anonymizing the data, strictly using the data only for common good, not using the data for commercial purposes and limiting the harm that can be caused to the individuals because of use of their data for epidemiological research (Unique Identification Authority of India 2016; Vayena et al. 2015).

Concerns of Equity in Access to Big Data Analytics and Benefits of Big Data

As described previously Big Data analytics requires specific skills and capacity which is more in the developed world. However, data generators are there everywhere as mobile phones and Internet access are nearly universal. Moreover, Big Data analytics is global in nature, thus providing easy access of data from the low- and middle-income countries to high-income countries. There is often a disproportion in the Big Data analytic capacity and quantum of digital epidemiological data generation. Huge volumes of digital data are generated in the low- and middle-income countries, whereas these countries have scant capacity for Big Data analytics and digital epidemiology. Thus, while the risks of breach of privacy are more among the huge volume of Big Data generators in the low- and middle-income countries, the benefits of digital epidemiology are disproportionately high in the high-income countries. This is a major equity concern which needs to be addressed by appropriate standard practices of data sharing and capacity building in low- and middle-income countries. One of the main concerns of topical importance in India is the linkage of AADHAAR unique citizen identity to health-care provision and its implications for Big Data and digital epidemiology.

AADHAAR Unique Identity Linkage to Health Care

AADHAAR is a 12-digit random number allotted to citizens who voluntarily choose to enrol. It is offered by the Unique Identification Authority of India (UIDAI). It collects basic demographic details of each individual along with biometric details such as ten finger prints, two iris scans and a facial photograph (Viktor and Kenneth 2013). The Government of India is increasingly linking many of its services and benefits to AADHAAR so that they reach the most appropriate persons. AADHAAR linkage to the Public Distribution System of foods under the Food Security Act and AADHAAR linkage of bank accounts and Income Tax Permanent Account Number (PAN) have been implemented (WHO 2016). The AADHAAR linkage has several advantages such as accurate targeting of social entitlements and benefits. A major potential that AADHAAR linkage of public services offers is clarity of identity of individuals.

The health sector has started using the AADHAAR application for many of its services. The DigiLocker is a cloud storage area of 1 GB that is offered to all citizens who register for it. The cloud space can be used for storage of important documents. Health records are also stored in this DigiLocker and this is being linked to AADHAAR. Under the National Rural Health Mission of 2005, the digital Health Management Information System has been established in the various states for tracking health-related data. Under this HMIS unique health identification number (UHID) is provided to each individual. The UHID is also being linked to AADHAAR. In many public hospitals like the All India Institutes of Medical Sciences (AIIMS), New Delhi, the Online Registration System (ORS) has been initiated for giving appointments for patients. This ORS is also AADHAAR linked. Health-related Direct Benefit Transfer (DBT) such as the Janani Suraksha Yojana cash benefit for women who undergo institutional delivery and nutrition supplements to patients on Directly Observed Treatment Short course (DOTS) for tuberculosis under the Revised National Tuberculosis Control Program (RNTCP) are all AADHAAR linked now. The National AIDS Control Organization (NACO) has also requested all persons living with HIV (PLHIV) to register their AADHAAR numbers with the program in order to better target the antiretroviral treatment. The Ministry has also announced an AADHAAR-linked Health Smart Card for the elderly to be piloted in 15 districts of the country in 2017–2018 (WHO 2016).

While all these sources of digital health information will help digital epidemiology in a major way, AADHAAR linkage of these data provides a clear and transparent access to the epidemiologist of clearly identifiable individual health information.

According to the AADHAAR Act 2016, the UIDAI can collect only minimal demographic information from the citizens such as name, date of birth and address and shall not collect information such as caste, tribe, ethnicity, language or medical details (World Health Organization 2017). However, the National Health Policy 2017 clearly articulates plans to explore linking health and medical data to AADHAAR (World Medical Association 2008). This raises important ethical concerns of privacy of individuals whose health data is accessible to the public health system, issues of autonomy and informed consent when such AADHAAR-linked health data is utilized for epidemiological research and the issue of data ownership.

Other countries that have such access to identifiable digital medical information have laws and regulations in place to control access to medical information. The General Data Protection Regulation of the European Commission provides for protection of personal data of each individual. However, it does not mention that the individuals have ownership of the medical data. It puts the onus of protection of individual rights and privacy on the government in a sense of stewardship. On the other hand, the United States has the Health Insurance Portability and Accountability Act (HIPAA), 1996, which provides full ownership of health and medical data to the individual. It poses strict regulations on who has access to this information.

In keeping with regulatory requirements, the Government of India has come up with the draft Electronic Health Records (EHR) Standards 2016 (Yadav and Arokiasamy 2014). The Standards affirm the need for a longitudinal electronic health record for every individual documenting each health-care encounter digitally in order to provide better, evidence-based care; enable accurate understanding of epidemiology of diseases; provide accurate treatments; reduce unnecessary health expenditure by avoiding unnecessary tests, procedures and treatments; and enable improved health policy-making. The Standards provide for AADHAAR linkage of EHR. The Standards state that the EHR generated by the health-care providers are “held in trust” by the providers on behalf of the patients. The data is owned by the patients themselves. Patients have full privileges to access their health-related data. They can restrict access to the data and will have to give explicit consent in order for their data to be accessed by others. The data shall be available to health-care providers on “as required on demand” basis. In case of emergency situations and national priority activities such as epidemics, or notifiable illnesses, the data may be shared with the authorities as mandated without the patients’ permission. In case the data has to be shared without individual consent, then it should be ensured that the data is completely anonymized. The Standards also provide for strict security provisions of EHR. Despite these provisions in the Standards, it is important to see how these ethical, legal and social issues (ELSI) are addressed in the long term, where this potential Big Data will be utilized for digital epidemiology.

While on the one hand the issue of privacy of individuals vis-a-vis electronic health records was being debated, the Supreme Court of India in a landmark judgement has pronounced privacy as an inalienable fundamental constitutional right in August 2017. This has overruled the older judgements which had ruled that privacy is not a fundamental right. The Supreme Court had charted out a three-tiered, graded approach to privacy as a fundamental constitutional right to individuals in India (Zwitter 2014). The first tier is that of intimate privacy of an individual comprising of marriage, family and sexuality. This tier should be fiercely protected, and any intrusion by the state should be carefully and strictly evaluated. The second tier of privacy is for data that is shared for specific purposes in the public domains such as credit card transactions, social media postings, income tax declarations, etc. It should be ensured that these data are protected to the extent that they are used only for the intended purpose and any other use of the data should be thoroughly evaluated from ethical, legal and social perspectives. The last tier is that of public domain where private data is shared in the public domain for purpose of common good. Examples of such data sharing include HMIS data. When personal data is in the public domain, it does not mean privacy is completely surrendered. It only means that the regulations of protection of privacy of such data are present, but not stringent. Given such heterogeneity of privacy, the Supreme Court had previously refused to identify it as a standalone homogeneous fundamental right under the constitution of India. However, the more recent judgement of identifying privacy as a constitutional right comes as a progressive respite towards a more robust liberal democracy in India. The other cases in front of the Supreme Court on the legal position of AADHAAR and its implications for privacy of individuals are still under considerations while this chapter is being drafted. The rulings on those cases will hopefully uphold this landmark judgement that privacy is a fundamental right.

Summary and Conclusions

Public health surveillance, digital epidemiology and Big Data analytics are important public health activities. Greater engagement of public health with technology has opened up a newer and more nuanced set of ethical considerations. This chapter has discussed key ethical issues in public health surveillance, digital epidemiology and Big Data. The important commonality in all the three activities is the huge quantum of data that is collected, stored, analysed, interpreted and used. In public health activities handling such massive amounts of data, the obvious and primary ethical concern is protection of privacy and confidentiality of the data. Public health warrants that a basic level of compromise to individual privacy and confidentiality may have to be accepted for producing common good to the broader community.

However, such a provision cannot be the basis for major violations of an individual's rights that are not justifiable. This chapter has highlighted that PHS, digital epidemiology and Big Data all are essential public health activities, and there is an ethical imperative to perform them. However, while performing such data-intensive activities, adequate safeguards to individual privacy, confidentiality, autonomy and rights have to be kept in mind and operationalized to ensure fairness. The Indian public health system has entered in a big way into electronic health records and digital health data. In this context, ethical, legal and social implications of the use of digital health data need to be carefully considered. Balanced ethical oversight of public health and epidemiological activities needs to be developed as top priority, and public health institutes in the country have to take a leadership role in developing ethical oversight mechanism and capacity.

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Chapter 8
Ethical Issues and Challenges in Research on Gender, Reproductive Technologies and Market

Sarojini Nadimpally and Deepa Venkatachalam

Abstract This chapter seeks to contextualize Sama's work on assisted reproductive technologies and commercial surrogacy from a bioethical framework. It discusses several ethical issues that are implicated in this burgeoning industry, the foremost being the stigmatization of childlessness and essentialization of motherhood that push women particularly to access ARTs (Assisted Reproductive Technologies). Secondly, even when regulation was initiated, many countries including India adopt a discriminatory approach to exclude LGBTI people from accessing these technologies and limit them within heteronormative marriage. Thirdly, the use of donor gametes extracted from others and surrogate mothers bearing a pregnancy and contractually relinquishing the child upon birth (with or without a commercial transaction) raises ethical concerns about the commodification and instrumental use of the body and its parts within the ART industry. Fourthly, there remain ethical questions on trade in biological materials that are "leftover" or "surplus", particularly embryos, and what can be the ethical parameters within which they can be used for further research and experimentation. An understanding of commercial surrogacy in India would be incomplete without discussing what the lack of regulation with regard to the practice of surrogacy has meant for the various actors of this mushrooming industry.

Keywords Reproductive technologies · Infertility · Egg donation · Surrogacy · Regulation · Ethics

In January 2014, a young woman, Yuma Sherpa, died during the oocyte retrieval procedure at a fertility clinic in Delhi. She along with her husband and 3-year-old daughter had come to Delhi in search of better employment opportunities—a trend that has become more pronounced during the last two decades with the increasing globalization of the Indian economy as well as the shrinking of employment opportunities, forcing people to migrate to big cities. Further, the majority of the migrant population in cities is employed in the informal sector where they work in highly precarious conditions without any financial, social or health security. Yuma Sherpa

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was one such person belonging to this vulnerable class of the migrant population in Delhi. She worked as a shop assistant and learnt from her neighbour that she could sell her eggs for Rs 25,000 to a fertility clinic. She may have possibly experienced some concern about the egg retrieval procedure as well as the stigma associated with the sale of oocytes. But, eventually, Yuma Sherpa decided to sell her oocytes; she went through the oocyte retrieval procedure in a private clinic during which 24 follicles were extracted from her ovaries. When she was shifted to the recovery room after the retrieval procedure, she felt uneasy and drowsy and became unconscious. She died a few hours later. The postmortem report of Yuma Sherpa suggested that she had suffered from ovarian hyperstimulation syndrome (OHSS), which is generally caused by the high doses of hormones to stimulate ovaries (Indian Express 2014).

While this case appears to be one of medical negligence where the concerned doctor at the clinic violated the guidelines of the Indian Council of Medical Research (ICMR) and the Medical Council of India (MCI), it raises serious ethical issues with regard to the assisted reproductive technologies (ARTs) including commercial surrogacy industry in India. In August 2010, Sushma Pandey, a 17-year-old who worked in a scrap depot, died in a Mumbai hospital. This was following severe abdominal pain over 2 days, suspected adverse effects of OHSS after she had donated eggs for the third time within a year and a half. Although the Mumbai High Court had asked for her death to be investigated, no one was held accountable (Majumdar 2014). It is likely that the unfortunate and avoidable circumstances that led to Yuma Sherpa's and Sushma Pandey's demise are not uncommon.

Media reports in June 2017 highlighted the "illegal confinement" of around 45–48 women acting as surrogates for the duration of their pregnancy in Hyderabad and in Bhongir (The News Minute 2017). The women who were "rescued" were from across the country with a few from the north-east of India and one from Nepal. Reportedly, they were gestating the children as part of commercial surrogacy agreements with commissioning parents, both non-resident Indians and foreign nationals. Media reports highlighted that the Hyderabad clinic received 15–30 lakh rupees for surrogacy arrangements of which only about 3 lakh rupees was to be given to the surrogate mothers. In the absence of a regulatory system, audits and reporting of data and information by the ART-surrogacy industry on success rates, complications, morbidities or even deaths, unethical practices are bound to prevail, and their consequences may never be known. This situation highlights the pressing need for regulation of the ART-surrogacy industry to encompass its vast as well as deeply entrenched networks. More importantly, it merits discussion on the nature and scope of the regulatory architecture as well as its limitations in the context of ethics, equity and rights.

Landscape of the ART-Surrogacy Industry

Over the last three decades, with new advancements in reproductive technologies and forces of globalization acquiring new vigour, the ART industry has witnessed the rapid global expansion (Pande 2010; Sama 2012). It has not only created a huge market for persons accessing services for infertility as well as people selling reproductive body parts like ova, sperm and uteri, but it has also provided impetus to new developments in the field of regenerative medicine such as stem cell research and therapy. That this industry in India is largely located in the private health sector is no coincidence nor by accident, given that the past three decades in the country has witnessed a major transformation that fostered the growth of a powerful private health-care sector. India has emerged as one of the most sought after global destinations for medical tourism, of which reproductive services constitute a substantial part. Moreover, this highly prolific ART industry built upon the new advancements in reproductive technologies buoys itself upon the social constructions of motherhood as women's destiny and compulsory parenthood, the desire to have one's own biological progeny and genetic essentialism which provides impetus for a "perfect" child.

In India, the expansion of the ART industry is most clearly visible, with these ART clinics in the largest of the metropolises to the remotest of the cities. However, since the ART industry in India is not regulated and the National Registry of ART Clinics and Banks in India (NRACBI) of the Indian Council of Medical Research (ICMR) not binding of the clinics, it is difficult to ascertain its size and contours. Available, albeit dated, estimates indicate that the surrogacy industry is worth $2.3 billion [Confederation of Indian Industries (CII) 2013], and other sources such as the National Commission for Women (NCW) estimated about 3000 clinics across India worth more than USD 400 million (Warner 2008; Kohli 2011) offering surrogacy services (Kannan 2009) to couples from North America, Australia, Europe and other continents. India's reputation as an extremely favourable destination for ARTs, especially for commercial surrogacy, is thus inevitable. Several reasons are responsible for the growth of this vast industry that is almost exclusively situated in the realm of unregulated private healthcare.

The unique and highly appealing combination of good quality services and technologies at comparatively cheaper rates is the claim by the industry in India. For instance, a surrogacy arrangement, including in vitro fertilization (IVF), costs about $11,000 (approximately Rs 5,00,000) in India, while in the USA, surrogacy alone, excluding ART charges, costs $15,000 (approximately Rs 6,75,000). A similar arrangement in the UK costs about £10,000 (approximately Rs 7,00,000). These indicate comparative lower costs of technological interventions as well as of contracting surrogacy services and arranging for genetic material. In addition to the clinics that are engaged in providing and promoting ARTs including surrogacy, the industry in India includes several other players; a wide array of organizations and personnel catering to clientele, both national and international; health-care consultants; various bodies associated with the hospitality industry; travel agencies; law firms; surrogacy agents; tourism departments; and surrogacy hostels. The ART industry that encompasses infertility services, IVF and surrogacy in different measures includes services to suit almost all pockets, from stand-alone clinics to corporate chains. The expansive and deep networks of players that comprise the industry provide diverse affiliated services at local, national and transnational levels. A significant number of the players promote their services through websites and design content to attract clientele, both domestic and international. Promotional strategies also use traditional religious networks involving religious institutions, especially in the case of overseas diaspora (Deepa et al. 2013). Advertising ART-surrogacy "packages" that offer incentives, discounts and "deals" with regard to the services provided. These generally combine boarding, lodging and other facilities for local tourism alongside claims of high success rates with ARTs and surrogacy arrangements. Part of such packages is the phenomenon of surrogacy hostels that facilitate surveillance and control over the surrogates. In such a scenario, given the context of global inequities and flows, what can/should be the frame of public health ethics and therefore regulation?

Infertility, Motherhood: Issues and Debates

The promotion of ARTs derives justification from the ideal construct of "motherhood as destiny" for women within a marital bond. Emerging from this logic, involuntary childlessness becomes a stigma and a social burden, and voluntary childlessness becomes a social "crime". For instance, primary studies illustrate that the failure to perform the mothering role results in unprecedented violence and harassment of women. Derogatory labels such as *banjh*, *banjhni (infertile/barren) or sukhi kokh (dry womb)* have been used for childless women, irrespective of whether the problem of infertility is with the men. These metaphors signify the prejudices and beliefs, which reinforce the responsibility of progeny on women.

On the other hand, reproduction has occupied a significant place in the feminist discourse as an area of subordination of women in patriarchal societies (Franklin 1995: 323). The technologization of the process of childbirth and the concentration of knowledge about the technologies largely dominated by men were perceived as divesting women of control over the process of reproduction. As an extension of this argument, assisted conception as a process of medicalization of reproduction, which in turn concentrated control in the hands of the ART provider. The ART-surrogacy industry undoubtedly reflects existing social arrangements and power relations, although in much more complex forms, which are dictated by the intersection of the political economy of infertility, market, labour and technology.

The labour market, for instance, is deeply gendered whether in a developed, newly industrialized or a developing country (Swaminathan 2009). Thus, women from hitherto and newly marginalized communities and regions find themselves more impoverished, powerless and vulnerable in the face of growing globalization of capital and the shrinking local avenues for jobs and resources. For these women, over a period of time, while access to traditional jobs and occupations has decreased, new markets have emerged for both their sexual and reproductive labour. Women's motivations to enter the ART-surrogacy industry as commercial surrogates and oocyte donors are primarily due to poverty and economic insecurity, including urgent financial needs or burden that they or their families are unable to address or cope with. Kaushik Sunder Rajan (2011) pertinently points out the existing position of exploitation, where surplus value of their labour is already extracted as part of existing or other industries or work options.

Commercial surrogacy pushes the limits of women's labour from the private to the public and from care to work. It brings reproductive labour into the market in an unprecedented manner and poses a challenge to these ideological constructs of the family, to the perceived separation of the family from the market and indeed to the very basis of kinship (Sama 2012). Some feminists, on the other hand, have critiqued the practice of surrogacy as reinforcing notions of biological kinship ties and increasing the social pressures of compulsory motherhood and hence stigma against infertility.

Surrogacy as an exceptional site of exploitation in a global flow of labour and outsourcing has been denounced by some feminists, while others have expressed concerns about the overriding concern for profits over health and objected to the use of the bodies of women of a certain class and region. Cooper and Waldby state that surrogacy and gamete donation represent new forms of embodied labour that have proliferated at the lower ends of this post-Fordist biomedical economy. They call this extensive yet unacknowledged labour force that the life science industries rely on and whose service consists in visceral experiences like tissue extraction, gestation and clinical labour. Amrita Pande (2010) argues that the surrogate is socialized to be a "mother-worker", in a way that her status as a mother is an insidious disciplining mechanism that undermines her status as a worker. Saravanan (2010) argues that the most important criteria for choosing surrogates are their submissiveness to the demands of the industry; the surrogates' location at the edge of poverty amplifies their vulnerability and poses serious threats to their health and rights.

Thus, in such a scenario, women's reproductive labour is being performed in a particular configuration that necessitates scrutiny of the norms as well as the rationale governing this labour once it is commercialized; and at the same time, it expects an examination of how the prevalent social norms and meanings are alternately negotiated and deployed. In practice, the conditions under which the surrogates perform this labour are often a mix of deployment of existing meanings of family and market and at the same time to ensure a "successful" outcome.

Experiences: Evidences from the Ground

Sama's[1] engagement with ARTs and commercial surrogacy through research and advocacy spans over a decade and resonates the spectrum of issues that have been discussed earlier. Sama's research (2006, 2010) on ARTs flagged the far-reaching

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[1] For over 10 years, Sama, a Delhi-based resource group for women and health, has been engaging with ARTs, raising and addressing concerns around gender and health rights that result from their unchecked proliferation. Sama's approach to the issues in ARTs has involved responses ranging from community to policy. Previous research initiatives on this issue contributed to unveiling the social, medical, ethical and economic implications of ARTs on the lives of women (ARTs and Women: Assistance in Reproduction or Subjugation?), as well as to deepening the understanding of commercialization of the ART industry as well as issues of access to these technologies in India (Constructing Conceptions: The Mapping of ARTs in India). These have enabled the location of

social, medical, psychological and economic implications for women and for society as a whole. Sama's work around ARTs is guided by the perspective that the interrelationship between reproductive technology and its end user is governed by gender, as well as by caste, class, religion, ethnicity, sexual orientation and other axes of power. Through research in the three states of Uttar Pradesh, Odisha and Tamil Nadu, Sama mapped the industry in India and the perspectives of doctors, clinicians as well as men and women who accessed ARTs. All of Sama's work on ARTs and subsequently on surrogacy examined the trope of motherhood from the perspective of medicalization and vivisection under ARTs and surrogacy. Sama endeavoured to link the micro and the macro, through themes such as market, technology, family, patriarchy, agency, regulation and so on. Sama's subsequent study on commercial surrogacy in Delhi and Punjab flagged the contrasts in terms of Delhi, because of the profusion of ART clinics that conduct surrogacy arrangements, being an accessible and established destination (as the national capital) for medical services and Punjab, with its diasporic links, and relatively nascent growth as a surrogacy centre in the region. The narratives of surrogates in the two sites foregrounded the issues in their entire journey of the surrogacy—with regard to recruitment, consent, medical regimen/practices, remuneration, contract, relinquishment as well as the stigma that they had to negotiate and experience throughout the pregnancy. The following sections of the paper draw on Sama's research with particular focus on ethical and other issues emerging in the context of commercial surrogacy.

Motivations to Be Surrogates

The socio-economic backgrounds of the surrogates from the study had a direct bearing upon their reasons for entry as well as the terms of the surrogacy arrangement. The 12 women in the study who came from similar economic backgrounds were invariably situated at the edge of poverty, had low education levels (apart from 2 who were graduates, the remaining had studied not more than class 10 or had not received any formal education) and were employed in low-paying, informal, casual work such as piece work in stitching – embroidery, domestic work, as cooks in catering units or as housewives. Their household monthly income ranged from Rs. 3000 to Rs. 15,000.

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discussions and debates on ARTs within the framework of women's health, rights and social justice and contributed to consolidation of existing knowledge, understanding and analysis of ARTs, the fertility industry and tourism. Sama has initiated and has been actively involved in ongoing policy advocacy efforts towards informing policy and legislation on the issue. Sama's work has thrown light on various aspects of this industry and the different actors involved showing different kinds of interactions and interfaces at multiple levels and the changing institutional forms and structures that have impacted the lives and conditions under which women have become a part of this industry.

Some women came from families that faced immediate needs, and along with their husbands, they bore the responsibility of paying off debts or buying a house. The appeal of commercial surrogacy was also in the fact that no other work option would enable them to earn such a large sum of money in a short span of time and this was the only way to realize their aspirations regarding securing their children's future and affording them education or some financial security by creating savings.

Several of the women had to convince their husbands to overcome their initial reluctance, about them becoming surrogates. Some surrogates also considered surrogacy as a better option than domestic work or factory work available to them. In a couple of cases, the surrogates also stated the persistence of the commissioning parents and agents was an important factor in them agreeing to take up surrogacy.

To Be a Surrogate: Criteria and Conditionalities

The intent of the women and the agreement of their spouses, however, were not sufficient for entry into surrogacy. The ART-surrogacy industry stipulates several criteria for surrogates that would ultimately contribute to the "successful outcomes" of the arrangement. These unwritten, albeit deeply entrenched criteria determine the inclusion or exclusion of women from entering and being part of surrogacy arrangements.

These include "proven" fertility, so that only women who have borne "healthy" children previously can qualify as surrogates. This qualification is also extended to imply that married women alone can become surrogates, reinforcing the socially acceptable norm of bearing children within heteronormative marital unions. This conditionality was also foreseen as necessary to avoiding any possibility of conflict regarding the pregnancy in case of single women.

The preference for married women as surrogates was justified as emerging from concerns about a successful and safe pregnancy, in the absence of previous pregnancies and child birth. Further, women were tested for various diseases or medical conditions to ascertain their "fitness" for the pregnancy. When diagnosed with a health issue, they were either treated or asked to seek treatment and return once "healthy". Doctors and agents confirmed that there were other criteria that were laid down by the intended parents including women from a particular (higher) caste and a particular religion, which often matched their identities. Other preferences expressed by intended parents on the lines of the surrogates' appearances as "healthy", "fair", "beautiful" and "hygienic" were usually accommodated. Most critically, submissiveness and pliability were seen as necessary qualities in women to become surrogates. These criteria above all else was central to the selection of the surrogates.

Similarly, the selection of gametes is mediated by the criteria of class, caste, ethnicity, education, intelligence, performance, etc. These conformed to and reinforced existing social hierarchies and prejudices concerning fertility, marriage as well as systems of caste and religion (Sama 2012).

The recruitment process involved a multilayered network that functioned via word of mouth and sometimes through advertisements in local newspapers. Some surrogates also transitioned into recruiters of other surrogates and were part of these entrenched networks. Similarly, entering the surrogacy arrangement was usually preceded by being an egg donor. This helped the women who were considering surrogacy to familiarize themselves with the medical processes and linked them to the recruitment networks that were active in the communities.

Access to Information and Informed Consent

Information provided to women, largely by agents, during initial interactions was limited and postured with the sole object of convincing them to enter surrogacy. Surrogacy was presented to the women as a wonderful opportunity to find much-needed relief from their financial stress, with an emphasis on the altruistic motivation behind surrogacy. Women were told that by agreeing to become surrogates, they would be giving the intended mother/parents a chance at motherhood/parenthood. The agents also emphasized that the conception would be achieved through technology and that they would not be engaging in sexual relations.

The processes of recruitment of egg donors from the communities are also known to follow similar patterns, with little or no information being provided about procedures, possible adverse effects, etc., which may facilitate an informed decision by the women.

Inaccess to information prevails throughout the surrogacy with women being provided scanty, if at all, any information about the several tests conducted, medication, procedures, remuneration, relinquishment, etc.

This control over information by agents, clinics and other players was also implemented proactively; women who were surrogates, even if from the same communities or undergoing procedures in the same clinic, were discouraged from interacting with each other.

The social stigma around commercial egg donation and surrogacy is gleaned by the industry in constructing and maintaining silences around this work that women do. This is different in surrogacy hostels where women stay together but are again in situations completely controlled by the clinic, agencies, etc.

Thus, processes of consent are neither informed and women are particularly discouraged from seeking information and making decisions independently.

The Medicalized Regimen

The necessity or "medical indication" behind the course the procedures take is questionable given that they are guided by the primary object of securing the birth of a healthy child and smooth relinquishment that accommodates the wishes of the commissioning parents. This is often placed above the possible consequences and concerns regarding the health of the surrogate or the egg donor. This was also evident in the case of Yuma Sherpa whose death was reportedly due to OHSS.

The surrogates were generally told that there would be no health risks and the pregnancy would be just like their previous ones. In the course of the pregnancy and thereafter, however, the surrogates in the study talk about the discomfort in having to follow the unanticipated aggressive routine of medication and injections, which they found to be extremely painful. They also report varied effects such as nausea, lack of appetite, swelling in the legs, extreme weakness, reduced mobility, weight gain after delivery and persistent pain from stitches following the caesarean operations that are generally the norm. Caesarean (c-section) delivery is followed as a standard practice even when it is not indicated medically; the clinics justify this as necessary to prevent any risk to the child/children. However, decisions regarding c-section deliveries are also determined by commissioning parents. For instance, the time of the delivery was also controlled to accommodate the commissioning parents' presence, on their request.

Given the low success rate of the technology, multiple embryo transfer is a standard practice, which in turn necessitates foetal reduction depending on the number of safe births possible and/or based on the preference of the commissioning parents.

The surrogates were given medication to prevent them from lactating; breastfeeding of the child by the surrogates is disallowed. This, according to the clinicians and agents, is necessary to prevent the building of any bond between the surrogate mother and the child.

The selection of "healthy" embryos at the time of transfer was also practised, leading to concerns of sex selection, although the doctors denied such a practice. Couples accessing ARTs (Sama 2010) have, however, indicated that selection is possible and practised by hospitals in the process of assisting conception.

Monitoring and Surveillance

Monitoring and surveillance were central to the surrogacy arrangement and clearly stemming from the assumption that the surrogate mother may attempt to sabotage the arrangement to their advantage. This assumption and belief form the basis of sustained surveillance of every aspect of the surrogate's lives. The possibility of such surveillance has been, in fact, employed as a promotional tactic to solicit further demand for surrogacy in India. The doctors, but most particularly agents, and surrogacy hostels facilitate the surveillance of surrogates. The ways of monitoring and ensuring compliance included surprise visits, phone calls, encouraging commissioning parents to keep a check, asking surrogates' husband or children to ensure she does not exert herself and asking the husband to give up his job and be available at home to take care of her and also through arrangement, where possible, of their accommodation in hostels or separate rooms through an agent/agency.

Attempts were made to monitor the lives of the surrogates during the pregnancy. For those who continued to live in their homes, diets were prescribed, including on the behest of the commissioning parents, and they were asked to eat only home-cooked food. Instructions were also given to keep their physical activity minimum and to discontinue with work outside and within the home. Surrogates expressed that such demands were contrary to their needs in daily life and difficult for them to follow. For surrogates in hostels/homes, stringent rules had to be followed regarding diet, physical activity, leisure activities, etc.

One of the critical demands made of surrogates was to abstain from having sexual relations with their husbands for at least the first 3 months and preferably throughout the pregnancy. For surrogates in hostels, they were allowed visitors but not allowed to go home for the entire period of the pregnancy. These hostels/homes were justified as necessary and supportive of surrogates by invisibilizing them towards preventing them being stigmatized by families and communities.

Contract and Remuneration

The contract between surrogates and commissioning parents was drawn up by lawyers hired by the commissioning parents or doctor; surrogates were not involved in this process, and no negotiation or discussion took place with them. The contract, in English in each surrogacy arrangement in the study, was not read by the surrogate nor by her husband; nor was it read out to them, and they were told only verbally what it states. Surrogates and their spouses were informed that the contract states that they agree to give up the child after birth. In one case there was mention of payment, though the surrogate was unaware of the exact details. The contract turns into a tool to minimize any conflict or contestation against the commissioning parents' rights to the child, leaving out a whole gambit of crucial issues that need to be negotiated and settled as the terms of the arrangement. It becomes a security for the commissioning parents, while the surrogates have none, with no control or say in the matter. Surrogates expressed their inability to afford any legal aid. Surrogate husbands' signatures were a mandatory requirement that raised very serious questions about her reproductive autonomy. A couple of women who were part of the study had to reconcile with their husbands who they had separated from due to violence because of the requirement of the husband's signature and agreement to the surrogacy. The remuneration for the surrogate has unfortunately become the peg on which the debate on "commercialization" is taking place. However, the remuneration paid to surrogates is but a very small percentage of the total amount of money that is transacted between the commissioning parents and the clinics and agents. For example, an agent in Sama's research stated that if about INR 20,00,000 is paid for the surrogacy package by the commissioning parents, only about INR 3,50,000 to 4,00,000 is paid to the surrogate. This amount quoted by the agent was much higher that what the surrogates in the study mentioned receiving, which ranged from INR 1,00,000 to 4,00,000 average being higher in Delhi. The amount paid to surrogates is mostly decided by the commissioning parents, clinics and/or the agents. In some instances, payments in the form of gifts after the birth, additional to the decided amount, or as promises to secure employment for one of the children of the surrogate (in one case) were also done. Surrogates' social locations/attributes also received additional payments from the commissioning parents. This was shared by an agent with reference to about rupees 1 lakh as additional amount paid to a surrogate from a "high" caste. Preference for specific social and physical attributes of gamete donors as well as surrogates has been a major ethical concern.

Payments were made mostly in instalments, with variations in the frequency and the amount disbursed. In some cases, a similar pattern was observed—INR 10,000 at transfer, INR 25,000 at confirmation of pregnancy and INR 6000–10,000 monthly expenditure; in some cases, the expenditure on travel for appointments at the clinic was included in the monthly expenditure, while in some the reimbursement was additional. Where agents had arranged for accommodation, they bore the expenses for travel or arranged for conveyance. There was also variation in allowance provided for hiring domestic help or diet consumption across cases. The common thread was that the bulk of the payment due to surrogates was made at the end of the pregnancy following relinquishment of the child/children.

In some of the arrangements, the surrogates were not even aware of the exact amount promised by the commissioning parents, with the agent/agency negotiating and paying on their behalf. Surrogates were unaware of the amount of the fee charged by agents or doctors, but some reported having observed that the doctors were paid significantly more. The agents reported that they had a fixed commission rate. In Delhi the agent deducted a commission fee from surrogates as well and had increased his rate consistently over the years. In Punjab, the agent reported that she claimed a flexible percentage, depending on the capacity of the commissioning parents to pay.

Relinquishment

There are constant attempts to create a "distance" between the child/children and the surrogates, to ensure relinquishment. The preference of using IVF technology and not using the surrogate's egg is motivated by the concern to ensure that she does not have any biological link with the child. The fact that the child was not conceived by their husbands was also reiterated by agents to impress upon the surrogates that they could not keep the child as it was not "theirs". Similarly, surrogates were denied breastfeeding and sometimes were also not permitted to see the child/children after the birth. After the delivery, the contact between the surrogates and commissioning parents was observed to be diminishing over time; in some cases, after the birth, there was no contact. The duration of contact is decided solely by the commissioning parents. Surrogates generally expressed the desire to have some contact and keep communication with the commissioning parents through the pregnancy and after birth, though some were sceptical of the possibility given the commissioning parents' preference of keeping the surrogacy a secret from the child/children in the future. Two of the surrogates expressed the desire to keep one of the twins they were carrying; however, their request was refused by the agents and the commissioning parents.

The Stigma

Stigma surrounding surrogacy diminished surrogates' power to negotiate, their invisibility, etc. Surrogates were apprehensive about what the perception of others regarding this work is and how it will/could affect them. They surmised that they would encounter responses that would equate surrogacy to sex work or baby-selling. As a result of the stigma attached to commercial surrogacy, the women very often chose not to tell their families, neighbourhood and workplace that they were part of such an arrangement. Some chose to move out of their own residence or cities to hide the pregnancy (Delhi), and those who stayed in their own homes negotiated these spaces by telling their families and neighbours that it was "their" child, reporting a stillborn after giving the child away, or that they were giving the child away to someone in the family (Punjab).

This predicament of stigma and invisibilizing was used by the commissioning parents, clinics and agents to negotiate terms that were in their favour as well as to create situations for the monitoring and surveillance of the surrogates. Commissioning couples, especially women, made attempts to maintain all medical records in their names, simulate a context of their pregnancy and were observed by some of the surrogates. Stigmatization and ostracism are extremely gendered and common experiences that are linked to infertility, often enforcing couples to maintain silence or secrecy about their "treatments" even from family members. Simultaneously, the growing ART industry deploys, and thus re/produces, the hetero-patriarchal institution of marriage followed by childbirth. Thus, women seek ARTs and expect to be able to transcend the stigma of childlessness and achieve some status with their families and communities.

Regulation

As transnational surrogacy moves across borders making parents and creating gestates—the use of ARTs continues to come under scrutiny. The lack of a comprehensive regulatory mechanism has resulted in the proliferation of the ART and surrogacy industry. This, combined with the growing legal complexities around surrogacy, has necessitated comprehensive regulation. The Indian government's regulatory efforts towards surrogacy under the broader umbrella of ARTs can be traced to 2005 when the ICMR, under the Ministry of Health and Family Welfare, formulated guidelines regarding ART and surrogacy. The ICMR guidelines, however, are non-enforceable, and hence in situations where there is an instance of negligence as in the case of Yuma Sherpa, there is a dearth of regulatory mechanisms to fix accountability.

However, the guidelines became the template for subsequent versions of the draft ART (Regulation) Bills since 2008–2014. Since 2012, the Indian government instituted restrictions on foreigners commissioning commercial surrogacy in India. However, the current proposed regulation, the Surrogacy (Regulation) Bill in 2016, limits itself to the practice of commercial surrogacy, sidelining the regulation of the vast ART industry.

The Surrogacy Bill 2016 prohibits commercial surrogacy in India, like in many other countries. It permits only "altruistic" surrogacy by a close relative for childless heterosexual Indian couples who have been married for 5 years. This, however, was the direction that regulation had been moving towards in the past years. Since 2015, the Ministry of Home Affairs (MHA) had stopped issuing visas to foreigners for commissioning a surrogacy. The Surrogacy Bill 2016 extends prohibitions that were included in the draft ART Bill of 2014 and permits only altruistic surrogacy (without payment) and only by "close relatives". This is permitted only for heterosexual Indian couples (excluding non-resident Indians), who have been married for a period of 5 years and do not have any children. The draft ART (Regulation) Bills (2010, 2014) mentioned marriage as a mandatory clause, with the "couple" who could access surrogacy arrangements, defined as a man and woman living in a marital relationship for 2 years; this has been extended to 5 years by the current Surrogacy Bill.

However, apart from the aspect of remuneration, there is no difference between a commercial or altruistic arrangement in terms of the medical procedures that are followed. Furthermore, vast ART industry, in which surrogacy arrangements, egg donation and other procedures for facilitating medically assisted reproduction are located, has been left largely untouched. At the time of this paper being submitted, there were no updates available about the draft Surrogacy Bill 2016.

However, the Department-related Parliamentary Standing Committee (PSC) on Health and Family Welfare examined the Surrogacy (Regulation) Bill 2016 and had placed its One Hundred and Second Report in the public domain. Some of the recommendations to the Surrogacy (Regulation) Bill 2016 by the PSC acknowledges and reiterates the autonomy and rights of the surrogates, which are appreciable.

However, concerns continue to persist in the Committee's recommendations that are briefly discussed in the paper. The Committee observes the "inordinate delay" in the follow-up of the Assisted Reproductive Technologies (ART) Bill, which includes provisions for regulation of ART/surrogacy facilities. Moreover, the PSC opines that bringing the "ART Bill before the Surrogacy (Regulation) Bill, 2016 would have been an ideal attempt for regulation of such clinics (Clause 5.93)" while asking to be apprised of the reasons behind the decision to draft a separate legislation for surrogacy.

This is an important issue given that the highly commercial and unregulated assisted reproductive technology (ART) industry, located overwhelmingly in the private health-care sector, has been completely let off from any efforts at regulation.

Since the Surrogacy Bill only permits gestational surrogacy, irrespective of whether commercial or altruistic, it involves procedures such as in vitro fertilization (IVF) and embryo transfer (ET), which entail a critical role for the IVF clinics. While it is important to focus on the phenomenon of surrogacy, at the same time, the ART industry that drives it must not remain beyond the realm of regulation.

The Committee recognizes surrogacy as "reproductive labour" and raises its concerns with regard to the proposed altruistic surrogacy arrangement. It says that "expecting a woman, that too, a close relative to be altruistic enough to become a surrogate and endure all hardships of the surrogacy procedure in the pregnancy period and post partum period is tantamount to another form of exploitation (Clause 5.20)". "Permitting women to provide reproductive labour for free to another person but preventing them from being paid for their reproductive labour is grossly unfair and arbitrary" (*Clause 5.18*). "Pregnancy is not a one minute job but a labour of nine months with far reaching implications regarding her health, her time and her family" (Clause 5.19). The PSC also acknowledges the "patriarchal family structure and power equations within families" and says that given this, not every member of the family may find it possible to refuse to be a surrogate when asked by another member of the family and that such a situation may be more exploitative than commercial surrogacy (Clause 5.21).

The Committee recommends the "compensated surrogacy model" instead of altruistic surrogacy. Here, "compensation" is a deliberate discursive choice, evident from its articulation of compensation. "The lost wages for the duration of pregnancy, medical screening and psychological counseling of surrogate; child care support or psychological counseling for surrogate mother's own child/ children, dietary supplements and medication, maternity clothing and post delivery care", according to the Committee, should be compensated to the surrogate. However, given that surrogate mothers are largely from marginalized backgrounds mostly involved in informal labour, characterized by poor conditions of employment and payment, "compensation" is based on the loss of wages which is first and foremost unjust and unethical. The surrogates should instead receive remuneration that is founded on the affirmation of the labour that is performed throughout the process of surrogacy and in keeping with the possible implications for her health as a result. The latter has been covered through the PSC's recommendation of insurance for a 6-year period following surrogacy regardless of whether or not it has a successful outcome (Clause 5.60).

However, the Committee's opinion on the requirement of consent from the husband of the surrogate (Clause 5.120) repudiates the Committee's firm stand on the reproductive autonomy of the surrogate. The paternalistic opinion sidelines the very autonomy it reiterates. The Committee has also not stipulated certain standards for the medical procedures—whether in the case of the extraction of oocytes or on informed consent of involved stakeholders or with regard to the transfer of embryos. The silence on some of these operational issues is concerning as the clinics can continue to practice unethical processes in this regard without the fear of being held accountable.

Conclusion

Nuanced, informed debates to foreground issues of the essentializing of motherhood, the promotion of compulsory parenthood for all and genetic essentialism, which are the foundations of the ART-surrogacy industry, are critical. Several ethical issues emerge vis-à-vis the industry's cash in on the patriarchal premium of having one's "own" biological child to maintain the purity of bloodlines. It thrives on providing impetus to the eugenic push for a "perfect" child. The appropriation of feminist language invoking "reproductive autonomy" and "women's right to choose" to safeguard their business by ART clinics needs to be challenged.

The falsity of the claims of the industry of a "win-win" situation for commissioning couples as well as surrogates has been emerging from evidence of the exploitation and unethical practices prevalent within. The power inequalities between the surrogates, egg donors, commissioning couples/those seeking ARTs and the clinics, doctors and agents are a reflection of the reinforcement of prevalent social as well as the medical hegemonies. Given that the industry and clinics are microcosms of these power hierarchies, can we and how do we envisage ethical praxis?

The death of Yuma Sherpa (the egg donor who died because of medical negligence) clearly revealed the unethical manner in which the ART/surrogacy clinics function without appropriate protocols, facilities and emergency medical care. It is also important to note the role of third party agents, surrogacy agents who play a key role in this industry but have never been under any kind of regulation.

As a public health issue, infertility has received very little attention; the discussion on infertility is nearly absent in the current debates. Services for infertility care, including basic screening facilities, are conspicuous by their absence in the public health system. Health services to address preventive and secondary causes of infertility are negligible driving most couples to access "treatment" for infertility, including ARTs in the private health-care sector. Larger questions of access, equity and affordability emerge here, given that access to ARTs-surrogacy is available primarily in the private health-care sector.

Moreover, although surrogacy is located in the larger ART industry, the attention to the latter has been in more recent times been diminished. This is also evident from the current trends in regulation of the industry in India. The ART industry is vast and deeply entrenched as has been discussed in the previous sections and urgently requires a comprehensive regulation to address the spectrum of unethical practices that evidence indicates. Sama has been demanding stringent regulation to address health risks for egg donors, for surrogates as well as women who access ARTs. Ethical issues involved in practices like embryo transfer, foetal reduction, number of surrogacies, age of surrogate mothers, etc. must be addressed through regulation as well as through enabling access to accurate information. Issues around fair payment, health care and insurance for surrogate mothers, issues around citizenship of the child if commissioned by non-Indians and the upholding the rights of surrogates and the rights of children born through surrogates need more deliberation and clarity.

The experiences of accessing ARTs have shown the significant financial, emotional and physical investment, in the long-term that could continue for years on end, perhaps without the desired result ever being achieved. This is also closely related to the collusion of markets and technology, whereby the unregulated and unethical industry controls access to and presents information selectively towards its own growth, ignoring the ethics of informed consent of those who seek services such as couples accessing ARTs or surrogacy as well as surrogates.

The current draft regulation for surrogacy as well as more recent drafts for regulation of ART clinics reflects extremely discriminatory provisions against “single” persons and queer couples, which are highly problematic, moralistic and inequitable. The limited rhetoric of the heteronormative family, marriage and nation has been extremely patronizing and violative.

Similarly, the shift to altruistic surrogacy and the assumption that this would be nonexploitative are both naïve and problematic. The exploitative nature of the “family” where women will be subjected to various kinds of pressures including coercion to act as surrogates is not unknown. It raises concerns since it is likely to obscure the precariousness of the conditions and vulnerability that may cause women to agree to such arrangements, by relationships of power and the lack of autonomy to make certain choices regarding reproduction and childbearing. Moreover, the argument of altruism is often extremely gendered and, in the case of surrogacy, steadfastly ignores women’s reproductive labour. Discussions around the practice of surrogacy must engage with the several issues and concerns discussed in the paper that go beyond the binary of commercial versus altruistic surrogacy.

In the entire discourse on regulation of commercial surrogacy, it is important to remember that the “commercial” aspect in this phenomenon is not limited to just the remuneration that the surrogate receives but the highly commercialized availability of ARTs in the private health-care sector. To regulate surrogacy in isolation from the larger milieu of ARTs translates into not addressing the vulnerabilities of women whose bodies are subjected to medically intrusive ARTs.

It is imperative that the women’s, ethics and public health movements strongly and effectively articulate their position(s) and concerns vis-a-vis ARTs and surrogacy towards an adequate response to the government's approach to regulation. For those of us who are asking for regulation of the industry, the basis is on the grounds discussed earlier, and also based on concerns regarding implementation in the context of an industry that has a widespread and deeply entrenched network, a ban might not address the situations that cause women to enter surrogacy arrangements and may possibly lead to an increased risk of black markets and further violations.

Ultimately, is the presence of an ART-surrogacy industry itself ethical that exploits the social, gender compulsions of motherhood? In a market-led scenario with its demand and supply logic, what therefore would be the frame for ethical practices?

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Part IV
Capacity Building in Public Health Ethics

Chapter 9
Public Health Ethics in the Medical College Curriculum: Challenges and Opportunities

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Abstract This chapter offers a historical background of medical education in India and the place of ethics within it. It traces the journey of training of the "medical graduate" in healthcare: from uniformity of competence to the social role of the physician and the evolution of aims of the current undergraduate medical education programme. There are several current challenges in medical education that run counter to the social role of the physician: commercialization of medical education, privatization of medical education, the hidden curriculum, basic degree vs. the basic doctor, basic doctor vs. the specialist, skill based vs. education based, technical vs. humanistic skills, cure vs. cause, and consequences vs. social determinants. The case of St. John's Medical College in Bangalore, with its historical institutional inspiration, and efforts to reach underserved areas, the evolution of the 2-year compulsory rural placement scheme on graduation, the pioneering effort at the introduction of medical ethics, and the community health outreach efforts have been highlighted. The outreach activities serve as a good stimulus for public health ethics as also public health research at the undergraduate and post-graduate levels. Challenges and opportunities exist in the conventional medical college setup and within the present medical curriculum in integrating public health ethics.

Keywords Education · Medical college · Ethics · Public health · Institutional history · India

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What Is the Aim of Medical Education in India?

The understanding of the role of the graduating medical doctor has crystallized over the years. At the turn of the twentieth century, The Indian Medical Act of 1916 aimed to ensure uniformity in the award of medical degrees across India. There were at the time, medical schools and colleges of different course durations, offering varied curricula. The intent was to move towards improved and uniform standards and in the process ensure a medical graduate with uniform competencies. The creation of the Medical Council of India by an Act of the Central Legislature in 1933 was a continuation of this process. In 1946, the Bhore Committee attempted to define the purpose of medical education in terms of the health problems of the country and the product of the medical education system. Thus, attention was drawn to the inequity in healthcare, the disparate health problems of rural and urban populations, and the need for the development of a "basic doctor". In making their recommendations with regard to the graduating medical doctor, the Bhore Committee (and reiterated in the Mudaliar Committee Report) kept in view the following principles that "The doctor of the future should be a social physician protecting the people and guiding them to healthier and happier life" and that "The training of the basic doctor should be designed to equip him for such social duties" (Government of India, 1959–1961, p. 20).

The Bhore Committee stressed the importance of preventive and social medicine in the medical curriculum – "Our 'basic' doctor's training includes, as an inseparable component, education in the community and preventive aspects of medicine" (Govt. of India 1946:340). This was a necessary requirement for medical students if they were to understand the social determinants of health and help the nation address these problems. This is further emphasized at a later stage in the report – "Preventive medicine leads easily to social medicine, and it is as exponents of the principles of social medicine that we would wish the 'basic' doctor to go forth into the world of medicine" (Govt. of India 1946:356). One of the first health reports of independent India continued to address the need for doctors to be part of the redressal of health inequalities in India. Thus, the first Prime Minister of India Pandit Jawaharlal Nehru would exhort the country in 1957: "While our cities and towns require to be looked after much better than they are at present, it is really the village that cries loudly for succor. Public health, must therefore, go to the village, and the village should not be compelled to come to the town in search of it" (Borkar 1957: vi). He was also very clear about the social determinants of health: "A war on disease and ill health is, therefore, essentially a war on poverty and all its evil brood".

The burgeoning of medical colleges in India, particularly from 1980, which by 2016 had witnessed a greater than threefold increase, is driven by a number of factors. The greatest increase in undergraduate medical college admissions during the period 1980–2016 came from private medical colleges which witnessed a 14-fold increase in admissions as opposed to a 66% increase in public medical colleges during the same period. This suggests a strong commercial aspect where medical education has evolved into a medical education industry. There are many problems with medical education in India (Sood and Adkoli 2000). This is reflected in the institution of capitation and exorbitant annual fees, reservation for high paying "NRI" (non-resident Indian) students, discretionary "management" seats, and a proliferation of private medical colleges run by entities unconnected with healthcare and driven by profit. The NEET (National Eligibility cum Entrance Test) entrance exam has been one of the attempts to root out corruption in the admission process to medical colleges.

At the same time, there is a real need to address not only the unflattering physician to population ratio in India but also the inequitable distribution of the doctors who graduate either in terms of the geographical locations they choose to work in (for instance, rural vs. urban), their ultimate specializations or nature of work, or the patient populations they work with. There are at present 474 medical colleges in India offering the basic MBBS degree, of which 222 (46.8%) are government and the rest private, administered by Trusts and Societies.

While a recent document of the Medical Council of India envisions an "Indian Medical Graduate" equipped with the requisite knowledge, skills, attitudes, values, and responsiveness so as to function effectively as a basic doctor – "physicians of first contact" for the community (MCI-Vision 2015) – it is clear that the basic MBBS degree of the medical graduate appears to have lost its sheen. Issues such as social status, peer pressure, earning capabilities, and the need to "recover" the costs of medical education tend to push medical graduates into further specialization. There is, thus, an overriding desire of medical students to "specialize" – post-graduation has become the goal – and, thereafter, the need to "super-specialize". Indeed, the MBBS degree appears to serve largely to distinguish between those trained in allopathic medicine and those who have graduated from other streams of medicine. In the process, the intent of the medical education system to produce "basic" doctors, competent at addressing the health needs of a community, has been lost, and generalists in the form of competent "general practitioners" are becoming scarce. The result of this trend is that fewer and fewer graduating medical doctors are able, or indeed, willing to align their training and practices to meet wider public health needs. This is glaringly evident in a recent review which has highlighted the disparity in the health workforce in rural versus urban areas (Goel et al. 2016). Indeed, one of the major reasons why medical students indicate that they might be willing to work in rural areas is to avail of the extra marks or reservation of seats in post-graduate courses (Jain et al. 2016). This dissonance between what is intended and what is achieved in medical education is not new, however, and has been the subject of extensive introspection even as much as 25 years ago (Mankad 1991).

Why Is Ethics Important as an Integral Part of the Medical Curriculum?

Through the course of history, a number of medical ethical scandals reached the attention of the public and resulted in well-defined directives or codes to guide medical practice and medical research. These include, in more recent times, the

Prussian Directive of 1900, the Reich Health Council Regulations of 1931 which followed the experiments of Albert Neisser in 1898, and large-scale introduction of the BCG vaccine in 1930 (Vollmann and Rolf 1996; Bonah 2002; Shuster 1997). The well-known Nuremberg Code following the horrific medical experiments of Nazi Germany in World War II and the setting up of various international bodies such as World Medical Association (1946), the United Nations' Universal Declaration of Human Rights (1948), and the International Covenant on Civil and Political Rights (1966) establish a high place for ethical practice and human rights in medicine and research. However, the teaching of medical ethics as part of the formal curriculum in medical school did not occur simultaneously with the development of ethical guidelines. Ethical scandals such as the Tuskegee Syphilis Study and the Guatemala Syphilis Experiments show that ethical behaviour of doctors could not be taken for granted based on the presence of guidelines or declarations. In addition, western models of bioethics have been critiqued to focus disproportionately on individual autonomy in healthcare (Clouser and Gert 1990), at the expense of a population level understanding and a preventive focus (Levy 1998).

While in the eyes of the public and the profession itself, the need for medical doctors to be ethical in their practice would seem to be self-evident, this has not always been so, either in medical schools or in the way medical students practised. Western medical education in India (apart from the Goa Medical School) was developed in British colonial India (Calcutta, Madras, and Bombay) and was influenced by the British medical education system. However, just a few decades before the start of the medical schools in India, medical students in Britain would be characterized as being foul-mouthed, indecent, callous, and cynical; they carried "the air of low men, of low habits…" (Newman 1957:41). At a time when anatomy had a pre-eminent position in the medical curriculum, *The Lancet* in 1832 would run an editorial in response to the West Port murders in Edinburgh where Irish immigrants Brendan "Dynes" Burke and William Hare sold the corpses of their 17 victims to provide material for dissection for students from Edinburgh Medical College – "It is disgusting to talk of anatomy as a science, whilst it is cultivated by means of practices which would disgrace a nation of cannibals".[1]

Much of this changed by the turn of the twentieth century. In 1923, Major General Sir Patrick Hehir, a student of the medical college of Calcutta who in his own words "spent the greater part of…life in India…in military life…in civil life, including that of lecturer in various subjects, health officer of a large municipality for ten years, general practitioner, and consulting physician", published a book entitled *The Medical Profession in India* (Hehir 1923, p. 2). In this book, he highlighted the lacunae of Indian medical colleges in comparison to those in the UK where "the ideals are loftier, the sense of duty and responsibility more fostered…and almost

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[1] Editorial in *The Lancet*, 1832. *The Lancet* in fact, during the years 1831–1832, would publish several letters related to the "Anatomy Bill", for instance, one signed in 1831, by "a Medical Student", calls for medical students "to unite in petitioning of the legislature during the ensuing session of Parliament for any act by which schools of anatomy in this country may be furnished with subjects for dissection with facility and without pecuniary demands".

insensibly the principle of service to others, are engrafted" (Hehir 1923, p. 35). While we cannot ascribe to Sir Patrick Hehir's views an importance beyond that of a single, if entrenched, observer of the medical education system in India at the time, it does highlight the fact that the medical education system in India was grappling with far more practical issues of curriculum and professionalization than with the idea of medical ethics. The ancient codes on medical ethics prevalent in India in classical Ayurveda which addressed wide-ranging issues such as behaviour as a student and a practitioner, the need for continued learning and interaction with peers, and the doctor-patient relationship, among others, appear to have found no place in the evolving medical curriculum in India (Wujastyk 2012). In 1916, the Indian Medical Degrees Act was promulgated (MCI 1916) and was a forerunner of the Indian Medical Council Act of 1956 the primary intent of which was to ensure uniformity in medical education for the award of degrees. Over a period of time, it appears that the implementation of these acts was achieved through a rather constrained prism of critical evaluation of medical education in terms of personnel and in the "traditional" course content. The primary process of evaluation was through "inspection".

In 1950, The World Medical Association (WMA) published a report on the "Standards of Medical Education" (WMA 1950) in 26 countries of the world including India in which the only reference to ethics was whether students took an oath on graduation, suggesting a global deficit in the formal education in ethics at that time. In the 1950s, The Medical Council of India and the Indian Medical Association had formulated codes of medical ethics, but the assumption appears to be that students would somehow imbibe these values during the course of their medical education, without any formal inclusion of medical ethics in the curriculum. Out of the 26 countries surveyed in the WMA report, students in Australia, Belgium, China, Ireland, India, Italy, Luxembourg, New Zealand, and Sweden, at that time, did not give any formal promise or undertaking as regards his/her future conduct on graduation or on receiving their licence to practice. There were limited steps taken to teach the medical students these codes of ethics during their course (as a part of medical jurisprudence), but education in medical ethics, in general, was not envisaged.

Among the many opinions on medical education expressed at the World Conference on Medical Education held in London in August 1953 (Govt. of India 1955) was an interesting observation by Raymond Whitehead where he criticized the description of an ideal student by Professor Samson Wright, a noted physiologist, according to whom an ideal student was "tall, handsome, of great personal integrity, beautifully mannered, highly intelligent…" Whitehead commented that that description was not of a medical student but a Greek God. "Let us remember that students are merely ourselves when young. Let us remember our own deficiencies – intellectual and moral…" (Govt. of India 1955, p. 33) he added. There, thus, appears to be an underlying sense that the training of medical students should extend beyond technical skills. However, the place of medical ethics in the curriculum appears not to have been discussed.

In 1955 a Medical Education Conference was convened in New Delhi under the auspices of Ministry of Health, Government of India. This conference had 111 delegates and observers from medical colleges and universities throughout India in addition to observers from other Southeast Asian countries such as Burma (Myanmar), Ceylon (Sri Lanka), China, Indonesia, and Thailand, as well as the Rockefeller Foundation and the World Health Organization. The aim of the conference was to critically examine the existing systems of premedical and medical education. This was a priority following independence in 1947 – "…the problem of raising the standard of professional training for different types of health workers and of expanding facilities for such training has been receiving continuous attention" (Govt. of India 1955, p. 1). This conference was significant on two counts in the context of this chapter:

1. It extensively discussed the need for enhanced emphasis on preventive and social medicine in the medical curriculum, in the light of the Bhore Committee Report. This, in a sense, attempted to place public health in a central position in the medical curriculum.
2. The conference specifically recognized the importance of including, for the first time, medical ethics in the undergraduate curriculum, alongside the study of the history of medicine – "The humanizing influence of a course in the history of medicine must be great because it brings home to the young medical student the high ideals and principles of medical ethics which actuated the leaders among the physicians of ancient India, Greece, Rome and Arabia in the practice of their profession in the service of the people" (p. 59). The conference suggested that a provision of 12 lectures in the history of medicine and 12 lectures on medical ethics must be made. However, no resolutions were passed on these subjects. A careful perusal of the proceedings of the conference suggests that deliberations of curriculum and clinical teaching in the "main" medical subjects pushed the medical ethics agenda to the background. This was a tragedy for medical ethics, which currently, more than 60 years following that conference, does not have a formal place in the medical curriculum.

Recent events have highlighted the need for medical ethics to assume a place of primacy in the medical curriculum. Corruption appears to be an integral part of healthcare, medical research, and medical education in India (Mahajan 2010; Chattopadhyay 2013), and this includes its regulatory authorities (Pandya 2009). Much to the dismay of Indians, this has also received considerable attention in prominent medical journals abroad (Berger 2014, 2017). Corruption can take the form of bribes and kickbacks to unscrupulous physicians and healthcare institutions, unethical marketing and sales of medicines, coercion of vulnerable populations to take part in research, inadequate compensation for participants in research, bribes for entry into medical colleges, nepotism and influence during promotions in medical colleges, among others. These and other corrupt practices erode faith and trust in the health systems and in public/patient-doctor relationship. While the teaching of medical ethics may not, alone, address these unethical practices, it is an important part of the many measures that can be taken.

What Is the St. John's Medical College Experience?

Extending Training to Ensure Socially Conscious Doctors

In 1963, the Catholic Church in India (Catholic Bishops Conference of India; CBCI) established St. John's Medical College at Bangalore. A significant focus of St. John's was its emphasis on meeting wider health needs, apart from the curative aspect of medicine. The Catholic Church in India is an important participant in healthcare. It does this directly through Catholic healthcare institutions (CBCI 2005). The Catholic Health Association of India (CHAI), for instance, has over 3500 member institutions. However, an important role of the Catholic church in healthcare is also through its participation in social development, education, and other fields which impact the health of individuals and communities. St John's Medical College was perceived as an apex institution which would provide leadership in healthcare and health promotion for this large network.

At the silver Jubilee of the Medical College, the founder Dean, Dr. Louis Monteiro, would write:

> The most important and significant development which is in keeping with the objectives, has been the active involvement of the College and the Hospital in rural areas….. at the end of the first decade, the College has extended and consolidated its activities in many villages, exposing the students (and the staff too) to the life, condition and health needs of the Indian rural people. (Monteiro 1988)

Ten years after St. John's started, there was, in fact, an attempt to review the progress of St. John's in relation to its stated aims. These deliberations were summarized in a Perspective Report to the CBCI on 11 January 1977 (St. John's Medical College 1977). One of the issues that was discussed at this stage was the social objectives of the college and the need to ensure services to the disadvantaged and rural areas. This first formal review of St. John's and its mission recognized many of the very real problems that could account for the failure of doctors opting to work in rural areas. It was this report which also highlighted the development of a scheme that would target rural service as part of an institutional commitment. From then on students admitted into St. John's were required to execute a bond to serve for a minimum of 2 years in a rural area following graduation. Since that time, large numbers of students both lay and particularly doctor sisters (religious nuns) have chosen to serve in rural areas of need, some for a fixed duration of 2 years following graduation and others for longer, including for a lifetime. As part of the preparation for rural service on graduation, several initiatives were undertaken to expose medical students to service in a community setting.

First, inspired by the Gujarat Milk Cooperative Movement, ACHARA, i.e., the Agency for Community Health Action in Rural Areas, was initiated at Mallur, about 35 km from St. John's Medical College, and was a tie-up with the existing milk cooperative in the locality. While there was an initial involvement of the Bangalore Dairy, the project continued even after Bangalore Dairy withdrew from the scheme and emerged as an example of a successful self-sustaining programme run by the people themselves (Joseph 1998). This health cooperative aimed at the development of a comprehensive scheme targeting the total development of villages with specific socio-economic and social health components. It was hoped that someday this scheme could be extended throughout the country and would involve individuals from many disciplines.

Second, in 1974, a Unit of the Ross Institute of Tropical Hygiene was established at St. John's Medical College with a full-time lecturer. The aims of the Ross Institute were focused around the issue of occupational health, the specific objectives being:

1. To study the occupational health problems of workers in industry, plantations, and also non-industrial occupations
2. To create an awareness and interest in the medical profession in the principles and practice of occupational health
3. To develop the field of occupational health through teaching and research and to organize seminars and symposia on important problems encountered in various industries

As a concept, certainly in medical schools, this unit of the Ross Institute was ahead of its times. Apart from its teaching and service roles, the Ross Institute played an important role in the outreach activities of St. John's Medical College through its work with tea plantation workers in South India and through studies of the health problems of home-based cottage industries in rural Karnataka including sericulture, weaving, etc. (Narayan 1979).

Third, the Bangladesh refugee crisis of 1971 saw the participation of over 25 students and interns in the first of many national disaster responses of the college. Later disaster response teams would address varying disasters in different parts of India and in neighbouring areas, including the super cyclone of Orissa in the 1990s, the tsunami in the Andaman and Nicobar Islands, flash floods in Uttaranchal, and the earthquake in Nepal, among many others. Disaster response teams functioned on a principle of volunteerism and emphasized the need of students and faculty to reach out to those in need.

In addition to the above, specific measures were undertaken in the medical curriculum to sensitize medical students to work among disadvantaged communities:

1. In 1981 a 2-week "Rural Orientation Programme (ROP)" was initiated for medical students soon after they completed the preclinical course of anatomy, physiology, and biochemistry. Students were required to spend 2 weeks in a rural area and interact with the local populace on a variety of issues including diets, occupations, cultural practices, and health practices, among others. At that time, the preclinical subjects were seen to be reductionist and dehumanizing – in part due to the anatomy dissections on human cadavers, the animal experiments in physiology and work with "samples" in biochemistry. The ROP served as a "rehumanizing" influence, placing the human person at the centre of medical training and sensitizing students about the social determinants of health, health inequities, and limitations in healthcare resources, among others. This exposure was at variance with the rigid biomedical model which tends to continue to dominate medical education.

2. In 1990, a second programme, called the "Community Health Action Program" (CHAP), was created for students in their third clinical year, with an urban and a rural component. In the URBAN component, students are taken on guided visits to institutions in the governmental and non-governmental sector, to observe and understand the role played by non-medical-/non-hospital-based players in the panorama of health and illness. Institutions visited deal with the terminally ill, the care of the elderly, the rehabilitation of street children, and the disabled, to name a few. In the RURAL component, the students visit villages and perform an analysis of the situation in relation to health, using qualitative and quantitative methods. They assess health of schoolchildren in the village and end by imparting an educational capsule to the community based on their study.
3. Initially, the rural training programmes of St. John's Medical College were based out of government primary health centres, through temporary residential arrangements established for the purpose. Over the years, a need was felt for a rural centre owned and administered by the institution. In 1992–1993, a "rural community health training centre" was constructed in Mugalur village, located about 30 kilometres from St. John's Medical College. Currently, all residential training programmes are based out of the Mugalur Community Health Training Centre. This centre serves as a primary care hospital, a base for several outreach service activities of the institution in addition to being a rural residential training centre for medical and allied health students. Medical students stay at this centre as part of their ROP and rural CHAP and return after their period of formal training to serve as interns at the centre. The experiential learning that takes place at the centre in itself helps in achieving the objectives of the programmes. In a reflective writing programme, students shared the impact the ROP has on them, calling it a "life-changing experience", that "robbed them of quite a few misconceptions" and opened their minds to a different perspective on rural service (Vaz and Timms 2016).
4. While the accent was on rural orientation and service in the 1990s and early 2000s, it became clear that urban populations were also experiencing great transitions in terms of health and illness. The proportion of the urban population in India has almost doubled in the past 50 years and comprises about 33% of the population currently.[2] With migration playing a role in the urban population mosaic, and cities being increasingly perceived as places of opportunity, the challenges faced in delivering health and welfare services to this huge heterogeneous population are immense. In order that medical students have an exposure to this population, an "urban orientation programme" was initiated in 2009 where students in their second year would visit and interact with families in urban underprivileged areas on topics related to health, nutrition, and other important issues. The objective of this programme was to sensitize students to the social determinants of urban health at first hand, so that they would see ill health not only as a germ, or agent-related issue, but as a sum total of several

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[2] World bank data: The United Nations Population Divisions World Urbanization Prospects, https://data.worldbank.org/indicator/SP.URB.TOTL.IN.ZS?locations=IN accessed 14.11.17.

factors which play a role in the balance between health and disease. In the words of a student in a reflective exercise post one such programme, "What good is our service to people, if we cannot stop the root cause, if there is a leak in a tap, would you only mop the floor or would you actually fix the leak? It is our social responsibility to educate, empower the defeated and strengthen the weak. If we tackle problems at the grass root level itself through small acts, it will ensure 'greater good'".

5. The medical curriculum is comprised of a four-and-a-half-year period of structured learning, followed by a 1-year period of "compulsory rotating internship" where the student is posted in the departments in the hospital to serve as part of the caregiving team and learn to apply all that he/she learned in the first part. This 1-year period includes a 2-month posting in community medicine, where the student is posted to a rural primary care centre to actually participate in the delivery of healthcare at a rural primary level. Typically, students learn about the need for effective communication, the need to adapt to a given situation, the need to use low-tech solutions at times, and the multiple factors that are associated with illness in rural populations.

Lessons Learned from These Initiatives

St. John's Medical College is not the only medical college in India to promote rural service after graduation. The Mahatma Gandhi Institute of Medical Sciences at Sevagram, Wardha, Maharashtra, and the Christian Medical College, Vellore, Tamil Nadu, are among other examples.

Through the initiatives at St. John's Medical College, several learnings have emerged:

(a) Most medical students come from non-rural backgrounds and are often exposed to the realities of rural life for the first time during their ROP. This serves as an eye opener in many ways, as evidenced by the presentations made by them to the faculty. It does serve to put the village on the healthcare map, sensitizing the students to the fact that rural healthcare is an important part of healthcare delivery in India.

(b) Actual visits to urban slums, studying the conditions therein and discussing their findings with faculty, help to broaden the students' horizons and see health as a part of a larger canvas. Classroom-based discussions on social determinants of health acquire a real perspective and make the student more holistic in their approach to illness.

(c) Being a mission-oriented institution, these programmes help to affirm the mission in real terms. The programmes do not aim to make all students serve their careers in rural areas but aim to sensitize them to apply the principles of humanism in their work, irrespective of the setting.

Experiences with Students

Using the existing Environmental Science classes and the Constitution of India classes that are prescribed by the Rajiv Gandhi University of Health Sciences, Karnataka, the Health and Humanities unit of St. John's brings a critical analysis of wider social problems into the classroom of first year medical students. Topics such as water scarcity, food security, consumption of resources, human rights, climate change, etc. are examined through newspaper articles, presentations by social-environmental activists, and film and documentary discussions. In addition, students conduct a survey of their immediate environment – the campus – and cover issues such as waste generation and waste management practices, water wastage and water conservation, fuel usage, and alternative options. Apart from developing a heightened sense of observation of factors in their surroundings that impact health, they are made to recognize their role in the problem, of causing harm, and their responsibility as citizens first and then as doctors to be responsive to the problem. Discussions include aspects of dignity of labour, the value of multiple skills and traditional knowledge, sustainable development, etc. Advocating solutions and alternative practices as a community of students for the betterment of their wider community is the ultimate aim of these classes. Movies such as the "Economics of Happiness" and "Erin Brockovich" bring to the fore the values of being responsive citizens, of making choices for the wider, common good, for standing up against injustice, and to mobilize communities towards change. Experiential methods such as the Theatre of the Oppressed are opportunities to experience the problem from the shoes of the other and address change from that reality. Sessions are also held on the importance of being a voter in a democracy, with the actual enabling of getting students registered on the voter's list as they turn 18.

A student initiative "Ecologics", a group that promotes environmental and social consciousness among their peers, conducts, among other things, cycling trips to the health centre at Mugalur to not only promote cycling but also to create awareness among the communities at Mugalur about a current disease, such as dengue. Cycling trips are also planned to other rural centres around Bangalore where the rural bond students are placed. *Ecologics* ensures that the annual inter-college student festival is held "ecologically" using recycled paper and reducing the use of recyclables to the extent possible. Recently, a decision was taken by the students, to convert the annual tree planting programme by the entrant and the passing out batches, into a tribute to the donors of the cadavers, their first teachers in human anatomy, in the form of an "eternal grove". These activities instil in students the values of caring for the environment, caring for others, the duty of a doctor beyond treating illnesses, and a sense of solidarity towards a common end and would be a stimulus or precursor for engagements on public health ethics.

Biomedical Ethics as a Central Focus of Medical Training

One of the primary objectives of St. John's Medical College at its inception was to "instil the principles of moral values into the students" so that they could maintain high professional standards and integrity of life. In order to meet this goal, medical ethics was introduced as a separate subject making it the first medical college in India to have ethics in the undergraduate curriculum (Ravindran et al. 1997). Initially, ethics classes were unstructured and informal, but later on the classes were taken by people who had received special training in medical ethics, and the teaching became more structured. The current ethics programme starts in the first year and continues into the 1-year internship programme. Students appreciate the formal instruction given to them as structured ethics classes, especially in the early years, which serve as a foundation in guiding their outlook:

> *In St. John's there are values that are taught to you, how to treat the person as a whole for example, we can see the difference when we meet students from other colleges.* (Study on the Hidden Curriculum, manuscript in preparation)

However, students in later years of the course question the applicability of specific ethics instructions in relation to the complex ground reality of patients and practical issues:

> Ethics classes are very idealistic for a real world…for example giving the patient the choice to do the HIV test, providing counselling, when the person comes to Emergency … we cannot put the entire hospital staff at risk. (Study on the Hidden Curriculum, manuscript in preparation)

Challenges and Opportunities to Include Public Health Ethics in the Medical Curriculum: Way Forward

There is little doubt that the current focus in medical education is very "biomedical"; medical graduates are trained in large hospitals, largely in urban areas with advanced laboratory and diagnostic services, technology, and facilities that are a far cry from those available for the vast majority of the population. Preventive and social medicine/community medicine/community health within the medical curriculum was intended to ensure that the medical graduate would acquire "broad public health competencies needed to solve health problems of the community with emphasis on health promotion, disease prevention, cost-effective interventions and follow up" (WHO-SEA 2010).

Current biomedical ethics teaching tends to be "principlist" in approach and confined to the ethical dynamics of the doctor-patient relationship. There is also a tendency to view medical ethics in terms of what is topical, even if limited in scope, as opposed to a more general and widespread ethical malaise. Thus, issues of end-of-life care, surrogacy, and freezing of ova and sperm are likely to evince greater interest among students compared to deaths due to malnutrition, avoidable maternal mortality, limited health access, and catastrophic health expenditure as a cause of poverty. Public health ethics requires a broader framework than that provided by a principlist approach and an understanding of larger community dynamics, as well as the roles played by multiple stakeholders including the state and civil society. In this context, it is worth remembering that traditional ethical frameworks in Asia have often been "communitarian" rather than "principlist".

One of the biggest challenges in incorporating public health ethics in the medical curriculum is the fact that both public health and medical ethics are generally not seen as central to undergraduate medical teaching, although considerable lip service is paid to both. There is also a large lacuna in the teaching of public health ethics even in institutions specifically devoted to public health education (Pati et al. 2014). Within the medical college, there are limitations to the translation of community health to public health, for instance, in the areas of health economics, health policy, and health systems, among others. In the face of this, what might be the approach and method to teaching public health ethics?

There has been some discussion about the approach to medical ethics teaching in medical schools. While the teaching of ethics as a separate subject confers on it an importance that it rightly deserves, there is a risk that medical students will see it as yet another subject that needs to be studied and largely forgotten, rather than having continued lessons for life. An alternative approach is to supplement the specific teaching in ethics, with an integrated approach that seeks to integrate the teaching of ethics into other subjects and in all situations (for instance, the bedside). Public health ethics in medical colleges in India might best be taught by incorporating it into the opportunities within the existing community health curriculum. This can be done without disrupting the existing teaching-learning programme and within existing time constraints, so as to appeal to students, and has been demonstrated in other subjects, like physiology (Savitha et al. 2017a, b).

While public health ethics has its own theoretical frameworks (Have et al. 2010), a more student-friendly approach might be to highlight and emphasize a few key themes. Benatar highlights three values that he suggests need to be promoted: concern for the common good, belief in and promotion of all human rights (and duties), and a sense of solidarity with others (Benatar 2003). Schroder-Back and others have suggested that a framework for public health ethics teaching and learning could be based on a set of mid-level ethical principles. In their own words:

> Such principles represent normative thinking that might stem from more than one moral philosophical theory and thus can be connected back to several theories. They are at the mid-point of a hierarchy that at its top is formed of overarching theories that attempt to explain and justify particular normative positions (for example, deontology and the preeminence of duty in moral consideration, or theories that focus on the importance of consequences in ethical deliberation); and at its bottom comprises a range of particular rules (expressed, say, through devices such as codes of conduct).

The seven principles include non-maleficence, beneficence, health maximization, efficiency, respect for autonomy, justice, and proportionality (Schröder-Bäck et al. 2014). The basic tenets of public health ethics have also been codified (Thomas et al. 2002), and these provide a succinct synthesis of various ethical issues that public health professions need to address. The World Health Organization has also developed ethical guidelines, specifically for public health surveillance, and it is important to note that these guidelines have been written in such a manner so as to be easily understood and implemented by the large community of health professionals (WHO 2017).

The current curriculum in community health through its lectures, case studies, and community and field visits lends itself to a significant opportunity for the learning and application of public health ethics by medical students. Many ethical issues that have been highlighted in this chapter are already issues that medical students are sensitized to, without specifically being located under the umbrella of "ethics". However, this learning needs to extend beyond knowledge and sensitization of issues to an ingrained way of thinking and acting where medical graduates are able to understand the ethical ramifications of interventions for the improvement of health in communities, and act on these. Medical education tends to foster a paternalistic approach to healthcare, and this is magnified in conditions of want and with health illiteracy. Ensuring public participation (procedural justice) in the development, implementation, and evaluation of public health programmes/interventions is not necessarily something that comes naturally to medical students and graduates who are daily witnesses of the power differential between the doctor and patient. Acceptance and respect for diverse values, beliefs, and cultures in a community and for the needs of disenfranchised community members are important issues that medical students need to learn, as also the need to ensure trust and transparency despite the higher status accorded to doctors in society. The paternalistic approach to healthcare is also compounded by the stringent hierarchy within the medical profession, with medical students at the bottom of the pecking order (Crowe et al. 2017). A more participatory approach to healthcare requires medical graduates to come out of an entrenched system that they have been a part of.

In order to achieve a start in the teaching of public health ethics in medical colleges, at least two things need to be done. First, faculty in community health departments need to be sensitized and trained about public health ethics, its dimensions, and importance. Prospectively, post-graduates of community health should undergo training in public health ethics, and this should be a part of their formal assessment. Second, a careful review of the Community Health Curriculum needs to be done in order to identify contemporary issues of need and where public health ethical principles can best be introduced, discussed, and debated.

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Chapter 10
"Now We Feel Ethics Is Everywhere": Reflections on Teaching a Course on Ethics in Public Health Practice

Arima Mishra

Abstract The need for an explicit nurturing of ethical lens to public health practice has been increasingly stated, yet such training is rare and/or inadequate. Very few public health education programs in India have an explicit module on public health ethics, and even where imparted, it is skewed towards biomedical and/or research ethics. This chapter takes the readers through a journey on designing and transacting a course on Ethics in Public Health Practice as part of a Master's Program in Development in Azim Premji University. It shows how clarity in learning objectives with pedagogical processes including case studies, simulations, film discussions and group work can go a long way in building capacity of public health professionals to develop skills in discerning ethical dilemmas and conceive of possibilities of resolutions through continuous deliberations and reflections. This course demystifies ethics as the prerogative of "ethicists" by bringing home the point that ethics is integral to public health practice and hence public health training must embed ethics explicitly and intentionally in its programs. It hence expands the discussion of public health ethics to include the wider canvas of public health practice including agenda setting, policy-making, program design, implementation and evaluation and research settings.

Keywords Public health ethics · Teaching · Empathy · Azim Premji University · Ethical deliberations

Introduction

In a response to a question on what kinds of ethical issues in health they have come across in their field work settings, one of my post-graduate students remarked, "Ethics is so integral to health. Everything about health has an ethical dimension so it is difficult to single out any specific issue". All public health professionals,

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irrespective of their training, roles and work settings, would resonate with this remark. However despite this recognition, understanding and application of ethical reasoning seem more assumed than consciously nurtured. The everyday ethical issues and dilemmas faced by public health professionals are increasingly coming to the fore (Baum et al. 2009; Khanna 2012, 2015; Posel and Ross 2014; Harper 2007; Banks et al. 2013; Bhan 2010). Such dilemmas cover a wide gamut of issues. For example, these include the following: How to promote health practices without infringing on individual freedom (e.g. promoting vaccination, institutional delivery)? Does administering directly observed therapy in tuberculosis program violate principles of confidentiality? How to communicate health messages that conflict with prevalent norms within a community (a particular religious group being averse to the benefits of vaccination)? How to reconcile potential conflict between legal norms and values of clinical practice (provision of MTP (Medical Terminantion of Pregancy) services by health providers not legally certified in response to community demands)? How to resolve the conflicting demands of the health system and that of the community, etc.? These dilemmas, whether in research sites, agenda setting and policy-making, design, implementation and evaluation of programs, health communication and advocacy in public health, are far from categorical or cut and dried issues. Hence a blanket application of medical/clinical ethics nor ethical codes developed in research settings are directly amenable to ethical analysis in public health (Holland 2010; Kass 2004). As discussed in Chap. 1 in this volume, ethical dilemmas in public health are far more complex and chaotic due to the very nature of public health enterprise itself that draws on different disciplines, research epistemologies and traditions (epidemiology, anthropology, participatory action research, etc.) and includes a wide array of functions (policy-making, monitoring and evaluation, surveillance, research, health communication), involvement of many actors (governments, community, non-governmental organizations, CSR and recently global health initiatives) and different kinds of interventions (ranging from vaccination to tax on high-fat food items to community-based monitoring). Its focus on population level health necessarily mandates public health practice to navigate through social inequalities, structures and norms of society to address the causes and consequences of ill health. Hence a societal understanding of public health and a critical and reflective practice through nuanced application of ethical reasoning is key to achieve the goals of public health. Yet public health professionals receive little training in building competency in applying ethical reasoning in their practice (Peckham and Hann 2010; Zodpey 2015; Schroder Back et al. 2014).

The need for adequate training in public health ethics has been explicitly stated, albeit only recently. There have been several initiatives including the establishment of Global Health Workforce Alliance and the Asia Pacific Alliance on Human Resources of Health (AAAH) in 2005, the report of the Joint Learning Initiative on Human Resources for Health (HRH) in 2004, The Committee at the National Institute of Medicine on "Who will keep the public healthy?" (2003) and the Lancet Commission on Education of Health Professionals for the twenty-first century (2010) to deliberate on public health education. These initiatives strongly call for revamping public health education that could respond to the current and future challenges of public health. Hurton (2010:1876) sums up the Lancet Commission's thrust as "….nothing less than a remoralisation of health professionals" education. Such a mammoth task requires, as the commission notes, innovations in institutions and instructions in teaching and learning. The commission recommends transformative learning that could help build competency in critical and analytical skills and more informed application of such skills in relevant contexts (Frenk et al. 2010). At the core of such educational efforts is to nurture health professionals to be socially responsible and accountable to the people they serve. The need for a more relevant and integrated curriculum that speaks to the needs of populations and health systems is strongly felt (Zodpey 2015; Hurton 2010). Specific efforts have been underway in thinking through innovative models of public health education and within that how to teach ethics in public health education. The Associations of Schools of Public Health with the Health Resource and Service Administration came up with an extensive model curriculum for teaching public health ethics along with other efforts (Jennings et al. 2003; Thomas 2003; Schroder-Back et al. 2014). Explicit discussions ensued on how best to teach public health ethics to promote practical application, should the teaching be intentional/explicit or embedded in overall programs, stand-alone course or through topics in different courses and a core or an elective, and most importantly what needs to be taught and how (Thomas 2003; Schroder-Back et al. 2014). It has however strongly been argued that teaching of ethics needs to be intentional and explicit as "it holds promise of training students to recognize hidden ethical assumptions, to consider them critically and to design and implement research and interventions that more fully achieve an ethical perspective" (Thomas 2003: 179). Such competencies need to aim at continuous reflections, deliberations and resolutions as ethical practice is not about a one off ethical clearance like in research proposals nor a mechanical application of frameworks and principles (Harper 2007; Holland 2010).

India has woken up only recently to the need for rigorous public health education that responds to the changing times and demands. The last decade in India witnesses increasing attention given to the domain of public health within the larger development goals. This is reflected in a spate of state-led programs and missions including the National Rural Health Mission, National Health Mission, National Nutrition Mission, National AYUSH (Ayurveda, Yoga, Naturopathy, Unani, Siddha and Homeopathy) Mission as well as several other initiatives spearheaded by NGOs/grass-root organizations and more recently the CSR (corporate social responsibility) activities. This is apart from the fact that India has been home to many large-scale public health programs whose implementation continues to be fraught with several challenges. While managing and implementing these programs and missions are an imperative, the evidence on persistent malnutrition, inequities in health outcomes, high out-of-pocket expenses, rapidly growing non-communicable diseases and introduction of new technologies reinstate the critical role of public health ethics as one grapples with the health challenges of the twenty-first-century India. In this context, concerns regarding quality and effective training of professionals involved in this sector loom large (Zodpey 2015; Pati et al. 2014).

Public health education institutions have begun to mushroom in India with very different thrusts, curriculum and pedagogy. In a review of public health educational programs in the country, Pati et al. (2014) argue that ethics courses are yet to find their rightful place in public health education. Only eight programs have a dedicated course/module on teaching of ethics. Most of the programs offering ethics target a very limited audience with life science and health science background leaving out a large chunk of professionals working in the field of health drawing from other disciplines. Most of the ethics courses are offered as short courses/seminars/ workshops or series of guest lectures and mostly focus on research ethics, bioethics and ethics and human rights. They also note that many of these programs have a skewed coverage of themes apart from the fact that ethics is taught in a didactic mode. Experiences of teaching in other contexts show that ethics cannot be taught through a select list of topics rather must be located within the larger perspectives of public health (Kessel 2003). The need for programs that teach ethics explicitly aiming at developing competencies in critical and ethical reasoning, team work and contextual applications of ethical principles through innovations in curriculum and pedagogy is repeatedly stated (Frenk et al. 2010; Thomas 2003; Kessel 2003; Schorder-Back et al. 2014). Reflecting on the limited coverage of articles in the journal of *Public Health Ethics*, Verweij and Dawson (2018:4) reiterate the need for more systematic research into teaching practices and the effectiveness of method in strengthening ethical sensitivity and skills. To address this critical training gap and the imperative of public health ethics, we, at Azim Premji University, have introduced a course on “Ethics in Public Health Practice” as part of a Master’s in Development program. This chapter reflects on the author’s experiences of developing and teaching this course seeking to contribute to the discussion on capacity building in public health ethics, which in India, is at a nascent stage.

Designing the Course

The idea of a course on Ethics in Public Health Practice emerged during a visioning meeting on mapping public health education in India organized by the University in 2014 where representatives of major public health institutions had participated. One of the participants raised a provocative question: “What are we training public health professional for? Is it for the market or to be able to respond to national needs?” This question provided a forum for deliberation on the multidisciplinary nature of public health, goals of public health and the perceived threats of increasing medicalization and technologization of health neglecting the social determinants of health. Participants reiterated the fact that public health has a social purpose that puts the “public” and “health” (broader sense of including curative, preventive and promotive) at the centre and the training programs must aim at reinstating this social purpose through building critical and ethical thinking with relevant skills. Teaching public health values and ethics, hence nurturing socially committed reflective public health practitioners, was discussed thread bare including should ethics and values of public health be taught as a separate course or through a set of foundational courses, should this run throughout the program, how should one ensure that such learning enable continuous reflections, etc. This meeting was followed by a consultative workshop, we organized in 2015, with public health professionals who have had experience of teaching ethics or engaging with ethics in public health research where the specific question of what works in teaching ethics (curriculum, pedagogy) was discussed. We presented a skeleton curriculum structure to the group inviting comments and feedback. Based on this, we (one of my former colleagues and I) developed the course which was then peer reviewed independently by two colleagues outside the university before this was placed for internal review and approval in the Curriculum and Pedagogy Committee in the University that has the mandate of reviewing all courses across programs in the University.

We had a specific set of considerations in mind while developing the course content. These included the following: (i) the course should speak to the program objectives within which it is located, (ii) clear articulation of the learning outcomes and developing students' assessments to fulfil these, (iii) the profile of students joining the program and who are likely to opt for this course, (iv) the content should have a balance of breadth and depth including developing perspectives with application skills and cover issues/case studies in the realms of health policy-making, implementation of programs and public health research broadly constituting the terrain of "public health practice" (thus not limited to research settings) and (v) inclusion of pedagogical tools that enhance students' skills in deliberations and reflections.

Ethics in Public Health Practice Within the Master's in Development Program

Location of a public health ethics course whether within a medical college, school of public health or a university is important as the course is embedded within the larger mandates of the institution and objectives of the program. The Azim Premji University is an endowment-based not-for-profit private university committed to a *social* purpose. Set up in 2010 by the Azim Premji Foundation that has been working in the field of strengthening school education for close to two decades, the university visions itself to contribute to a just, humane, equitable and sustainable society.[1] As part of this vision, along with several other activities including research, field practice and continuing education programs, it has launched masters' programs (in Development, Education, Public Policy and Governance, Law and Development) to prepare students to contribute to the social sector. The Ethics in Public Health Practice course is offered as part of the 2 years Master's in Development program. The aim of the program is to nurture students to become *reflective development practitioners* and leaders of social change. It seeks to "prepare individuals

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[1] The university was set up under the Karnataka State University Act in 2010. See for more details about the university www.azimpremjiuniversity.edu.in.

to become aware of the complexity, depth and scope of the discourse of development, its ethical imperatives and its implications for policy and action with special reference to the Indian context" (Azim Premji University 2018). The admission process is designed carefully to enrol students from diverse backgrounds (profession, geography, gender, social background and work experience) who share a common passion to work in the social sector.

Flowing from this program objective, the curriculum is designed to build competencies in theoretically informed and methodologically grounded development practice. The curriculum has eight core courses in the first two semesters in year I followed by a range of electives in different domains within Development in the subsequent semesters in year II (Public health, Livelihoods, Sustainability, Policy and Governance, etc.). The core courses lay the foundation of approaching the ideas and practices of Development from different disciplinary lenses as well as hands on courses like Skills in Development Practice and Introduction to Research. Ethics in Public Health Practice is offered as an elective in the last semester (semester IV). Hence it draws on students' learning from the foundational courses, select electives as well as engagement with the field through three rounds of field practice (Field Immersion, Field Internship and Independent Field Project of 2, 6 and 8 weeks' duration of being in the "field", respectively).

Course Content

Locating the course within the program objectives, the curriculum and pedagogical requirements of the university and drawing on experiences of teaching public health ethics in other contexts, we developed the syllabus of the course. To begin with, we specified the learning objectives which provided the frame for what (the content of the course) and how (pedagogical tools) should the course be taught including how students be assessed.[2] The course envisaged developing three specific competencies to develop among the students at the end of the course. These competencies include ability to (a) discern/identify an ethical issue; (b) deliberate individually and in group settings through bringing out the nuances of the ethical challenge, multiple perspectives, relevant application and adaptation of ethical guidelines; and (c) conceive of multiple possibilities of resolutions. These competencies rested on students' understanding of public health perspectives, goals, foundations, frameworks and ethical tenets of public health ethics and their unfolding (nuanced application) in varied contexts including health policy-making (including priority setting), design, implementation and evaluation of programs and research settings. The ethics discussions in these varied settings of policy, program and research allowed students to have a wider canvass of public health practice (beyond research) as they are likely to be involved in different roles in these work settings once they graduate.

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[2] See for details on course goals vs learning objectives https://teach.its.uiowa.edu/sites/teach.its.uiowa.edu/files/docs/docs/Goals_vs_Objectives_ed.pdf accessed on November 17, 2017.

Keeping the learning objectives in mind, the course is structured into four units. The first unit delves deep into locating public health ethics as a distinct field (from medical and bioethics) unpacking understanding of "public" and "health". It brings home the lager message that public health ethics rests on a *societal* understanding of public health that upholds values of equity, rights and justice and locates health necessarily in the larger social, political and economic arrangements of a society. Contrasted with clinical and bioethics, it expands its scope and orientation to include understanding of communities, health systems, global health initiatives and actors and their role in public health policy and practice. Unit 1 takes students through the different ethical principles and frameworks (utilitarianism, liberalism, deontology, feminism) while conveying that application of these principles is not straightforward and needs continuous deliberation and application. Flowing from these larger perspectives, the rest three units help students navigate, appreciate and crack ethical issues and challenges in specific contexts of health policies, programs and research (including advocacy). The last class wraps it up through students' reflections on their learning.

The assessments are continuous and progressive. It has four components (Table 10.1). Students are evaluated on the nature of their class participation throughout the course (20%), case study analysis in groups (25%) and developing case study idea by individual students (35%) which has an additional component of presentation of case studies ideas to the class and the instructor (20%). The two major components thus are development of a case study idea (it can be an advocacy campaign, research study, piloting an intervention idea, evaluation of a scheme/program, communication strategy for a health promotion idea) by individual students to assess how students have learnt to embed public health ethics in the work they do. Detailed guidelines for developing individual case studies are shared with students (see Box 10.1). Students are expected to present their case study idea to the class and elicit feedback to help them develop it further. Additional feedback on the drafts is provided individually to students by the instructor outside the class room. This also ensures that students are thinking through this idea and developing it iteratively. The group case study analysis precedes this. Since one of the key elements of public health ethics is enabling students to deliberate and resolve in group settings (required in their work life), the second important component in the assessment is

Table 10.1 Evaluation criteria

Nature of assignment	Weightage %	Timeline
Group work on case study analysis (identification and collaborative resolutions in public health ethics)	25%	6th week
Participation in class discussion	20	Continuous
Individual presentation of case ideas to the class eliciting peer and instructor's feedback	20	10th week
Incorporation of feedback and development and writing of the case study	35	15th week

Box 10.1 Guidelines for individual case study ideas

By the end of the course, you are expected to have a solid grasp of how to embed public health ethics in the work that you do. Hence this assignment expects you to come up with a project in the nature of a research proposal, an evaluation of an existing intervention, implementation guide for an existing program, designing a health scheme, or an advocacy campaign around an issue or any other project of your choice. This is an individual activity. Irrespective of the nature of the project, the following pointers will help you as you design your project and assimilate the learnings from this course. You should use the lenses of equity, rights, vulnerability, risk and social justice while embedding public health ethical concerns into your project.

1. Why choose this particular theme for the project? What is the process of defining the problem at hand (e.g. evidence on burden, impact evaluation, etc. think of all the information at hand that help you to define the problem, problem for whom, is this really a priority)? (link to distributive justice/priority setting/cost-benefit analysis/efficiency)
2. What is the goal of the project?
3. Identify who are the stakeholders in this project (what are their moral norms/claims/authority and how might these impact the definition of the problem, process of achieving the goal of this project, what potential conflicts does one envisage among different perspectives and how might one resolve these).
4. Will there be specific groups of stakeholders who will be differently impacted as a result of your project? For example, will one group be impacted more or less and why would this be the case? Keep the relational power in mind (focus on equity lens and keep questions of who will it benefit and how in mind).
5. How will you ensure that public/community participation is retained in your projects? Please think carefully at which stage you will include public (who would be part of this public) participation, why and how (link to procedural justice, individual/community consent).
6. Do you see any potential conflicts between public health ethics and legal requirements or organizational conflicts in your projects? Or any other conflicts you may anticipate in the settings of work (e.g. research setting/a specific organizational setting, e.g. if your project involves working with adult married women and you realize that women are married early which potentially conflict with legal and marital age)? If so clearly state them and think about how you might address them.
7. Think of how context (broader political, economic as well as specific cultural settings) influences the ethical analysis of issues involved in your specific project (e.g. vaccination, why MR vaccine was resisted by parents due to a rumour).

case study analysis in group settings. Students are provided with one case study each and a set of guiding questions to analyse this. Each group presents it to the class and responds to questions/discussions.

The course is transacted over a semester with 16 weeks with a total 48 contact hours (3 hours in each week) with additional office hours for individual case study feedback. A total of 21 students in one batch (2015–2017) had opted for this elective. They were drawn from various backgrounds but had already done three semesters in the program together thus having a shared understanding of development. All of them have had some engagement (either through field projects or electives) with the health domain including broad understanding of the health system issues and challenges in the Indian and global context as well as encounters with ethical challenges in their field settings.

Pedagogical Processes and Tools

Learning to Empathize and Raise Questions

A course on Ethics in Public Health Practice cannot be learnt and/or taught from a social distance (as a distant commentator) assuming it to be a technical exercise of applying universal ethical standards and guidelines. Kleinman (1999:72) rightly cautions:

> The irrelevance of ethics can be seen when considering universal ethical formulations of justice and equity that do not begin with local moral conditions of poor people, those experiencing the systematic injustice of higher disease rates and fewer health care resources, because of their positioning in the bottom of the local social structures of power. Dealing with issues of justice in the absence of such contextual concerns renders ethical formulations mere speculations, utopian pronouncements that are gratuitous and beside the point.

Sensitivity and empathizing with issues, experiences and outcomes of people in different contexts or what Guillemin and Gillam (2015) call "ethical mindfulness" is critical for any meaningful engagement with ethical practice. Empathy and greater self-awareness are at the heart of developing reflexivity which is important for understanding human experiences, discerning ethical challenges, unravelling complexities of such challenges and thinking of ways to address these. There has been increasing engagement with such ethical mindfulness through pedagogical tools of reflective writing, narratives, simulations and discussion of case studies specifically in the fields of medicine and nursing (Dasgupta and Charon 2004; Porter and Ventakatapuram 2012; Walsh 2011; Diekelmann 2001).

Following from this turn towards the need for empathy in understanding public health ethics, the course uses simulation, narratives, case studies and films. The course begins with a simulation exercise of "Power Walk" which takes the students on an experiential journey of health inequity where students are able to visualize how society is organized and power and resources are distributed unequally across different social positions (caste, class, age, gender, region, religion, specific health conditions) and what it feels to be in a position of power (or powerless).[3] This exercise elicits a rich discussion of inequity (what is unnatural, unfair about it), values that uphold a certain societal order and naturalizes or questions inequity (market justice, social justice), responsibility for health (individual or collective) and what each one of us irrespective of our roles can contribute to this collective enterprise of public health.[4]

The first week also uses a real story covered in the media on Chhattisgarh sterilization tragedy (2014) where 11 women died and many more hospitalized due to related complications. The discussion elicited students' reactions, thought processes, emotions to questions on why is it called a tragedy, who and what is at stake, who are the stakeholders and what are their perspectives and students' views on these perspectives, etc. While students distinctly see this as a "failure of conscience" sharing their feelings of anger, sadness and frustration, they also raised several questions about accountability of officials involved in one of India's largest and oldest health and family welfare programs and the role of the state vis-a-vis the poor tribal women in planning family for their individual benefits as well as nation's good, problematic of choice and informed consent, gendered nature of family planning (with skewed focus on female sterilization), etc. The story served well in the initial week for a more open-ended discussion because (i) it dealt with an extreme adverse event where the moral and ethical failures were evident, (ii) students were well versed in the objectives of this program and (iii) information cited in the media was limited allowing students to think of other actors who seemed invisible in the narration of the incident and their perspectives, additional information (students who have worked on reproductive health issues cited information, experiences from their field work) and questions needed to address this. This rather open-ended discussion allowed reinstating the need for public health ethics. It helped the class to open up and learn from each other in *responding* to an adverse event like this. The ways they related to this event were reflected in their verbal gestures/emotions as well as framing several questions. Not all students were equally forthcoming in sharing their views in the first instance but gradually learnt from one another as some students shared their usual inhibitions of "is this the right question to ask?, "Is this an ethical issue?". Valuing the forum of a class room discussion, one of the students at the end of the course reflects:

> This course has been a personal journey for me where I constantly have fought within myself trying to understand the confusions that emerged once we started unravelling the different sides of the issue at hand and multiple perspectives. I felt everybody was right including myself. But then if everybody is right, how does one move forward? I felt that only a class room could provide a liberal space where I could express this confusion as I myself listened to my class mates who had different experiences/perspectives to share. I learnt what it means to navigate through different viewpoints, to talk about shared understanding of a problem and possible resolutions. Ethics is humane and it is important that one looks within first before trying to address any other issues out there.

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[3] Power Walk is widely used in training on gender, equity lens in program implementation, etc. in different settings. The simulation exercise can be widely adapted to suit the contexts and requirements of learning objectives. See for more details Pradhan et al. (2010), UNICEF https://www.unicef.org/tdad/jjpowerwalk.do.

[4] This discussion is informed by Beauchamp (1999), Kass (2004) and Holland (2010), among others.

Collective Deliberations Through Discussions of Films, Case Study Analysis and Group Work

Watching and discussing the film on Miss Evers’ Boys (1997) took the students to the next level of complexity of issues and concerns. While the film addresses the infamous Tuskegee experiment in medicine and the unethical nature of human experiments (thus a clear prerogative of medical ethics), the film succinctly captures different perspectives and their reasoning, the continuous dilemmas of the main protagonist (the nurse Miss Evers), role of science, weighing risks and benefits (including what constitutes benefits, whose benefits) and role of contexts in ethics (racism, resource poor settings, power and information asymmetry) while introducing students to notions of risk, harm, deceptions, evidence/data, fairness, informed consent, health communication, etc. which they encountered throughout the course. In addition, the film titled “Something Like a War” (2003) also worked well in eliciting rich discussion on consent, coercion, science, individual vis-a-vis larger good, vulnerability and procedural justice in the context of large-scale public health program. Films have been used as an effective pedagogical tool in discussing ethical principles in medicine (Searight and Allmayer 2014). However it is not the films per se but how the discussion unfolds in a class setting is equally critical.

The use of case study methodology in public health ethics in enhancing active student learning in appreciating the complexity, decision-making skills and application of philosophical principles to real-world contexts and understanding different multiple perspectives has been widely noted (Bhan 2010; Howard et al. 2004; Braunack-Mayer 2010; Schroder Back et al. 2014). This methodology helps in discussing ethical issues because the issues discussed in public health are not very clear cut thus allowing a relatively open-ended discussion on how to apply ethical principles and reasoning to situations that students could relate to. One of the important objectives of the case study methodology is to help students build capacity for working in groups thus drawing on each other’s personal and professional experience/moral worlds while discussing the issues at hand. The conflicts that may possibly occur and ways that the members of the group resolve are critical to the process of deliberations and resolutions.

Considering the size of the class, students were divided into four groups with five students in each with one group having six. Each of them was given a case study. The overall guidelines remain the same for all. However specific questions to provoke discussion were provided for each of the case studies. The guiding questions were important as the course gradually sought to develop the ability to identify and raise ethical questions. The selection of case studies was based on the consideration that these covered different kinds of public health issues and different settings. Students were asked to present both the processes of deliberation (what happened in the group discussion) and its outcomes. Students greatly appreciated the case study methodology and analysis though they did share that the group deliberations were tough. They wrote this in their reflection notes:

> Discussing case studies helped us gain a realistic understanding of ethical issues. I possibly cannot imagine taking this course without having discussed specific real cases.
>
> Though exciting, it was equally challenging to discuss the case study. We debated and differed significantly in identifying what the ethical issue was in the case study. Resolutions of the issue were tougher. Our group discussed the case study on situating reproductive rights. Some thought it was family planning and the conflict between a 'nanny' state and individual choice was the key ethical issue while I thought it was about reproductive rights and access to safe abortion services (for which there is a law that defines what is right and wrong). Perhaps it was somewhere our own gender background and specific experiences that were coming in our way to do the case study analysis. At the end of the discussion, I felt I still had many unanswered questions raised about the case study than any resolution yet it was a strange feeling because I did not realize that even a case study on such a familiar theme could raise so many questions. So I feel good to have identified the same though do not have the answers

Each group had a different experience to share and each chose its own ways to present it. While one group acted out the different characters in the case study, others divided the work presenting each aspect of the case study analysis. The presentations revealed the group dynamics and often disagreements surfaced during the presentation. The group case study analysis was meant to draw students' attention to the difficulty and complexity of decision-making process in teams in any organizational setting. The presentations to the larger group and feedback helped soothing some of the unresolved issues and broadening the contours of analysis in some cases. The case study analysis elicited different reactions. Some felt relieved to be able to see through issues in a systematic way, while for some others it led to moments of frustration saying things are so complex and everything seems problematic. Such frustration is natural as a student confided that:

> I had never thought that one needs to ask so many questions in understanding what happens and why it happens. As a natural tendency, we feel comfortable in asking the surface level questions. Deepening inquiry unsettles our minds but I understand it is necessary. Social justice is not business as usual.

Some of these settled down when they started developing individual case study. We discussed at length why resolution does not mean a clear-cut solution rather continuous deliberations and reflections (knowing and weighing the consequences of specific decisions in a particular context and time informed by ethical principles) in itself are part of the resolution. During class discussions, case scenarios were also included that had reflective accounts of the authors of resolving the dilemmas in a specific way. Students were asked to think through how they would respond to the way the ethical issue was resolved and if they were in the same position and context, would they have done differently and why so.

For individual case studies, students chose a range of ideas. Some students chose to revisit their earlier work done either as part of an organization or independent field project to approach it afresh through an ethical lens. Some others developed new case study ideas in developing a communication campaign on sanitation in a slum area, evaluation of existing health insurance schemes, community mental health program or a formative research on assessing the feasibility of a community-based intervention to address malnutrition among children.

Conclusion

Teaching this course has been a collective journey with the students. Like any other collective enterprise, we have had our moments of pessimism, sadness as well as hopes and elation in a shared endeavour. My experiences of offering a course like this also have made me realize the need and immense scope in taking on the role of a "co-learner" while being a facilitator, where a response or reaction from the students has been the lead for a dimension I had not planned. Many such responses evolved when engaging with one another's experiences and perspectives. Students interestingly expanded understanding and application of existing concepts including consent or beneficence. Another important reflection is that courses such as this one can have clear-cut learning objectives, but the processes do have to evolve organically both in terms of methodology development and student engagement. Hence a course (even as I offer it second time as I write this chapter) is dynamic and evolves in terms of student engagement in responding to the case scenarios and thinking of resolutions and nature of collective deliberations.

The course is meant to expand students' horizon in applying an ethical lens and not a routine application of guidelines, and it reasonably succeeded in doing the same. One of the students shares her learning of the course:

> Before opting for this course, I had a general, surface understanding of ethics. But the various layers of what it really means to work ethically were peeled and explored only in this class. It was in this course that we went about discussing consent, for example, beyond a written consent form. We learned how in practice consent goes much beyond a thumb print or signature on a piece of paper that we as researchers use to get an ethical approval. The course for me was crucial in terms of discussing and deliberating ethics in our work and the nuances of it. It set a base for raising the correct questions in any research or intervention that we intend to be a part of. It has helped me gain clarity about the guiding principles that would help me resolve any ethical dilemmas that would arise when I go to apply my learnings of my MA Development programme to the real world challenges

Another student shares a light moment at the end of the course saying "Now we feel ethics is everywhere".

The objectives, course content and pedagogical measures of such courses are not self-contained or complete. This is at best forms the foundational tenet and trigger for students and young practitioners to start the self-reflective evolution of their journey in health ethics. One of the biggest risks for such well-intentioned efforts is to look at it as complete when it is only the first step in the process of learning itself in a field full of complexity and change. The goal of public health is large, and one needs concerted efforts to nurture socially and ethically committed health professionals to work for this noble endeavour. The university is uniquely positioned through its continuing educations programs, field connect and masters' programs to reach out to many professionals seeking to contribute to public health practice to join this shared journey in learning Ethics in Public Health Practice.[5]

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[5] The university offers a week-long course on Ethics in public health practice to in-service professionals; see www.azimpremjiuniversity.edu.in/http://azimpremjiuniversity.edu.in/SitePages/University-resource-centre-events-ethics-in-public-health-practice-2018.aspx.

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Correction to: Data Ethics in Epidemiology: Autonomy, Privacy, Confidentiality and Justice

Vijayaprasad Gopichandran and Varalakshmi Elango

Correction to:
Chapter 7 in: A. Mishra, K. Subbiah (eds.), *Ethics in Public Health Practice in India*, https://doi.org/10.1007/978-981-13-2450-5_7

The original version of Chapter 7 was inadvertently published with incorrect surname of the second author. The surname of the second author was presented incorrectly as Elang. The correct surname of the second author should read Elango.

The chapter has been updated.

The updated online version of this chapter can be found at
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