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Preface

This volume addresses the overlapping aspects of the fields of genomics, obesity and (food) ethics. It is unique in its examination of the implications of genomics for obesity from an ethical perspective. Genomics covers the sciences and technologies involved in the pathways that DNA takes until the organism is completely built and sustained: the range of genes (DNA), transcriptor factors, enhancers, promoters, RNA (copy of DNA), proteins, metabolism of cell, cellular interactions, organisms. Genomics offers a holistic approach, which, when applied to obesity, can have surprising and disturbing implications for the existing networks tackling this phenomenon and for fundamental ethical notions, strategies and practices. In the book several strategies to match genomics, obesity, society and ethics are studied, and a happy match is proposed based on a pragmatist ethical framework. The ethical framework presented is inspired by the interaction between a procedural perspective emphasizing the necessity of consultative and participatory organizational relationships in the new interfaces between (nutri)genomics, medicine and food, and a substantive perspective that both cherishes individual autonomy and embeds it in socio-cultural contexts.

The research for this study was done partly in 2003 and 2004, and partly in 2008 and 2009, due to severe work overload and other duties to be done in the interim period. The contributors were so kind to update their chapters, so the delay in publishing has, as far as I can assess, not lead to outdated pieces of information, but on the contrary enabled to cover a broad temporal window.

Working with this team of contributors was quite a delight, and I am very grateful to the many comments and interesting insights that were exchanged during our interactions on this subject and that illuminated me in writing the chapters, outlining the general structure and scope of the book and doing the editorial work.

Wageningen, The Netherlands — Michiel Korthals

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About the Authors

Henk van den Belt studied sociology at the University of Groningen. Since 1989 he is assistant professor at the Applied Philosophy Group of Wageningen University. His PhD thesis is a historical and theoretical critique of Ludwik Fleck's pioneering constructivist work on the genesis of the Wassermann test and modern concepts of syphilis. His current research centers on the institutionalization of ethics in science policy, worldwide cultural differences in the socio-ethical evaluation of biotechnology applications and the relation between global justices and global inequalities.

Jozef Keulartz (1947) is Associate Professor Applied Philosophy at Wageningen University and Research Centre, the Netherlands. He has been appointed special chair for Environmental Philosophy at the Radboud University Nijmegen, the Netherlands. He has published extensively in different areas of science and technology studies, social and political philosophy, bioethics, environmental ethics and nature policy. His books include Die verkehrte Welt des Jürgen Habermas [The Topsy-Turvy World of Jürgen Habermas, 1995], Van bestraffing naar behandeling [From Punishment to Treatment, 1996, 4th ed), Struggle for Nature – A Critique of Radical Ecology (1998), and Werken aan de grens – een pragmatische visie op natuur en milieu [Boundary-Work: A Pragmatist View on Nature and Environment, 2005]. He is editor of Wilhelm Dilthey: Kritiek van de historische rede [Wilhelm Dilthey: Critique of Historical Reason, 1994] and co-editor of Foucault herdenken [In Memory of Foucault, 1995], Museum Aarde [Museum Earth, 1997], Pragmatist Ethics for a Technological Culture (2002), and Legitimacy in European Nature Conservation Policy (2008). Keulartz is a participant in ALTER-net, a 'network of excellence' funded by the EU's 6th Framework Programme. He is a member of the Scientific Council of The European Centre for Nature Conservation (ECNC). He is also a member of the Netherlands Commission on Genetic Modification (GOGEM).

Michiel Korthals (1949) is Professor and Chair of Applied Philosophy at Wageningen University. He studied Philosophy, Sociology, German and Anthropology at the University of Amsterdam and the Karl Ruprecht Universität in Heidelberg. His academic interests include deliberative theories, American Pragmatism and bioethics, and ethical problems concerning food production and

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Mara Miele is senior fellow at the School of City and Regional Planning at Cardiff University since 2004. Previously was senior lecturer at Pisa University, Italy. She obtained her first degree in Agricultural Economics at Pisa University and her PhD in Rural Sociology at Wageningen University. Her academic interests include food consumption practices and human/non human animals' relationships. Mara Miele research has included a range of projects concerned in different ways with the ethic and aesthetic of practices and materialities of food consumption, looking at the boundaries between ordinary-ness and reflexivi-ness of such practices in everyday life. Empirically, she has been committed to qualitative and ethnographic research. She is currently member of the Steering Committee of the EU VI framework project Welfare Quality, coordinating the qualitative investigation of consumers' attitudes towards animal welfare in seven EU member states. She is also participating in an ESRC funded project on school meals where she is conducting an investigation on children food consumption habits and the role of school meals in Italy and in the UK.

Maartje Schermer is associate professor of medical ethics and philosophy of medicine at Erasmus University Medical Center, Rotterdam. Her main research topics are neuro-ethics, human enhancement, the ethical and social implications of new technologies and autonomy. Her background is in medicine (MD) and philosophy (PhD, University of Amsterdam); she has published widely on a variety of topics. She is presently working on research projects on human enhancement, neuroethics, and genomics.

Tsjalling Swierstra (1960) studied in Groningen and Amsterdam. He graduated *cum laude* in philosophy in 1987 and *cum laude* in political science in 1988, both at the University of Amsterdam. He received his PhD in 1998 at the University of Groningen. His dissertation, *De sofocratische verleiding* [The sophocratic temptation; nominated for the biannual prize for best dissertation in political science] defends the thesis that dominant conceptions of practical reason still bear the imprint of by now out-dated (empiricist or rationalist) conceptions of theoretical reason/science. In 1996 he joined the philosophy department of Twente University, where he teaches ethics and social philosophy. In 2009, Tsjalling Swierstra has been named Professor by Special Appointment of Philosophy and Ethics in the life sciences, from a humanistic perspective at the University of Amsterdam, Faculty of Science and in 2010 followed his appointment as Professor of Philosophy at Maastricht University. He researches philosophical, ethical, questions concerning technology in general, and concerning medical biotechnology in particular. He has received several grants. In recent years he published articles and books on cloning, new reproductive technologies, genomics, technology ethics in general, and on the ethics of New and Emerging Science and Technology (so-called NEST-ethics) in particular.

Part I
Introduction

Chapter 1
Challenges of Genomics to Obesity and Traditional Ethics

Michiel Korthals

The Problem

No one will have failed to notice that the 21st century will be the century of genomics and biotechnology or more broadly of the life sciences. In the last decade of the 20th century citizens of developed countries were confronted with questions like: Which gene is responsible for which characteristic? How are the activities of genes influenced by other genes and by other environmental factors such as diet? How can one determine which food is healthy for which person with certain genetic characteristics? Will the life sciences not only permit to develop food and medicines engineered to each person's specific DNA, but even to purposefully (re)construct its applicants? The next decade saw a multiplication of these questions.

Genomics is a process and its prospects and innovation trajectories change continuously. A highlight was the completion of the DNA sequence of the human genome announced by Craig Venter (head of private owned company Celera Genomics), and Francis Collins (director, NIH National Human Genome Research Institute) in June 2000. US-President Clinton hailed it as the uncovering of 'the book of mankind', as 'the code of life'. The imminent arrival of applications through genetic testing, and genetic products were prophesied in jubilant tone by many. DNA pills were announced to abound in a few years. The largest Dutch newspaper *De Telegraaf*, published in the apt time of national food-indulgence (Christmas) an article:

> *A first for the Netherlands*
> Loose Kilos with DNA-pills by Martijn Koolhoven AMSTERDAM – At the eve of Christmas USA and Netherlands do get an interesting first for people who want to reach quickly their ideal weight: the DNA-pill. American and Dutch scientists succeeded after years of research in developing a formula with which it is possible on the base of personal DNA to produce a pill with which the customer in a few month can reach his or her ideal weight. Superfluous kilos disappear without slimming. Every customer gets his or her own peculiar pill, produced on the base of his or her own DNA. According to the company

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Salugen Inc. metabolism and weight of the customer can be healthy again in an average of three months (Saturday December 24, 2005)

The article got 266 reactions very quickly. A lot of people ask for self diagnostic tools and devices. DNA and other genetic and genomics terms are becoming now and then even media hypes because so many people are interested in testing or self testing of e.g. cholesterol, blood pressure, and PSA (a measure for prostate cancer). Some producers are eager to jump in that market niche. So, there emerges a broad spectrum from at the one end serious testing for one or more heredetic diseases to at the other end innocent but unclear caring devices like massaging-your-DNA-apparatus, face saunas, and self illusion apparatus. In fact, these kinds of media hype do happen more often (see Chapter 14) and again and again some people are seduced to buy the miracle pills or tests with the aim to prolong their life, or even to enhance their performances. It makes it clear how controversial and inspirational the life sciences are and that many feel it necessary to become potential winners and not losers of these sciences and to step in as early as possible.

From the nineties on, genetic determinism and genetic health were seen as either positive or negative phenomena and aroused hot debates in the Western mass media. The proponents predicted a new area of human progress, because humans could now control genetic changes (see Peters, 1996; Smith, 2005; Stephenson, 2008). The opponents feared discrimination against genetic handicapped people, decreasing respect for privacy, apathy because of genetic determinism and the increasing power of genetic drug and food companies (compare Jasanoff, 2005).

But slowly during the last decade the focus of research of genomics changed from the genomes of plants, animals or humans towards the interaction between genes and between genes and their environment. It turned out that the genome is only part of the book of mankind or the code of life, if that exists at all. Articles in scientific and more popular journals appeared that warned for hasty applications and they even predicted that the dream of genetic health and food will remain a dream for ever. Articles in renowned journals appeared with titles as: Genetic profiling to promote a healthy life style: not ready for primetime (*Nature Genetics* 2003). Laying bare the functions of genes made it necessary to delve into their complex interactions with other genes and the environment. Holism or as it officially is called, system biology entered the scene. This changed the ethical issues and challenges as well.

Genetic determinism is becoming a less relevant scientific perspective, and the focus is now shifting towards complexities and multiple research trajectories connected with the much more complex questions raised by these interactions and their impact on health and food technologies and their final results, products and services. This network approach is now firmly established in all the ‘omics’ – branches, like proteomics (studying the genome of proteins; metabolomics, studying the genome of metaboles and other ‘omes’). And it became clear also in technological trajectories less at a distance of consumers, e.g. testing, that no quick solution does exist (GOA 2006).

This study deals with these changes while concentrating on the ethical implications and assumptions of genomics for obesity along conceptual and thematic lines. It will raise more questions than answers, but it is the business of philosophy to produce better questions, which in the end steer our attention to better answers. In order to do that, we will start with a conception of genomics that covers the sciences and technologies along the pathways DNA takes till finally the organism is built and sustained: the range of genes (DNA), transcriptor factors, enhancers, promoters, RNA (copy of DNA), proteins, metabolism of cell, cellular interactions, organisms. Genomics is, with other words, a holistic approach that covers both genes and the environment and can lead in the case of nutrigenomics, the application of genomics to nutritional sciences and food technology (Werf et al., 2001) to new drugs, services and food stuffs. One of the aims of nutrigenomics is to approach obesity or the metabolic syndrome, as is the term more often used in scientific circles, which is a collection of phenotypes combining inflammation, metabolic stress, insulin resistance and diabetes 2. This new approach can have surprising and disturbing implications for the existing, pre-genomics, networks tackling these phenomena and finally for the life styles of many. Obesity attracts large attention everywhere. It is seen by many as an epidemic and attracts growing attention of governments, industry, public health organizations because of its very serious negative medical consequences. The World Health Organisation (WHO) wrote a report in 2004 in which was stated that in 2020 50% of the world population could be overweight. The report signalled also the *double burden of nutrition* which means that populations are often simultaneously both underfed and overfed. Obesity is commonly measured in terms of the Body Mass Index (BMI), which means weight in kilograms per square of height in metres. In the US in some states 15–20% of the adults is obese and in some even more that 25% of the inhabitants (BMI >30). In the Netherlands 13% of the boys are overweight and 0.9% obese (BMI >30 kg/m^2) and of the girls 14% are overweight and 1.5% obese (more about this in Chapter 10). Many actors are involved and are held responsible and consequently, many blame each other.

Formally, everybody with a body mass index higher than 30 is catalogued as obese, but this simple calculation covers many social and ethical issues, like: is it a disease? What do the obese themselves say and experience? Has obesity something to do with a pre-established interaction between genes and environment? Who is responsible for all this fat and has to pay the bill? Should everyone be tested? Should we strive for personal diets for everyone? And what do food and drugs mean? The growing number of obese persons implies a growing health investment that is needed to manage the health problems of the more than billion people that are overweight and obese. Lots of agencies, actors and stakeholders are connected in networks that consist of at least three constellations: one that emphasizes the individual behaviour of the obese, a second that has the social contexts of obese persons as its core, and a third that centers on the body of the obese persons (more about this in Chapter 3). The mass of material about this topic and the number of questions

Fig. 1.1 This is not a pragmatist approach Ron Barnett, New York Times, 29-10-2006

one can ask sometimes seems inexhaustible. It is therefore time to start with a fresh and comprehensive presentation of the trends and developments. (Fig. 1.1)

The Perspective of This Study

The authors are motivated to study these developments of genomics, obesity and values (which we call: *co-evolution*) from an ethical perspective because of several reasons. The first is that indeed so many ethical concepts, values, institutions and intuitions play a decisive role in this field; informed choice, responsibility, good life, the common good, blaming of stakeholders, ethical and social committees are involved but also lots of social and material agencies that have ethical meaning as well. This broad, confusing and mixed range of elements requires ethical clarification, analysis and possibly assessment. Secondly, ethical analysis as the authors see it, can contribute to bridging the gap between genomics experts and people that are not often in daily life confronted with genomics, but are still affected by it. There is a constant push from the side of expert cultures of science and other involved professionals to exclude lay people, and we belief that an ethical analysis because of its holistic ambitions can indeed contribute to give a broader picture of the field and in that way contribute to a better public understanding of the meaning of genomics in daily life. In the book several strategies to match genomics, obesity, society and ethics are studied, and a happy match is proposed based on a pragmatist ethical framework.

This ethical framework is inspired by the interaction between two perspectives (which will be discussed later in Chapters 13 and 15 in much more detail). On the one hand we will elaborate upon a procedural perspective that emphasizes the necessity of consultative and participatory organizational relationships in these new grey zones between medicine and food. On the other hand, we enter upon a

substantive perspective that not only cherishes individual autonomy, but also the embedding of individual autonomy in sociocultural contexts (Keulartz et al., 2002; Korthals, 2001).

In this complex, multilayered context, we will travel along several trajectories of pragmatist's ethics, like analyzing the problem of obesity (according to the adagio 'better problems, not only better solutions', Chapters 3 and 4), dilemma construction and responsibility inventories (Chapters 5 and 6), scenario building (Chapter 7), following the problems (Chapters 8 and 9), comparative analysis of varying cultural framings of obesity (Chapters 10, 11, and 12) and important ethical trends (Chapters 13, 14, and 15) to clarify the main issues. The complicated problems in confused contexts, so characteristic for obesity, are discussed, like the issue of the many hands and of diffusion of responsibility (Chapter 6). The complexity of the problem is quadrupled by the application of genomics sciences and technologies to obesity and their influence on current ethical values, strategies, public arenas and life styles. This application creates shifts towards screening agencies and other kinds of new services and products to manage obesity, which determines new public responsibilities and new distributions of responsibility, but also new types of responsibilities for food professionals.

Plan of the Book

In Part I, Chapter 2 opens with a general introduction into the theme of genomics, health, and food. Health care and food production systems based on genomics and nutrigenomics will give rise to new grey zones and four new developments: these systems will be preventive instead of curative; individualizing in stead of collective; they will produce new types of risk perceptions for a healthy life; and they will give rise to the issues of selection and management of huge amounts of information. These four types of developments change the interfaces between scientists, producers (like food and medical professionals and their intermediaries), government regulators and consumers/patients socially and ethically. In each of these groups and between these groups changes take place (like the shifting relationship towards one's relatives in preparing and consuming a meal in the group of consumers/patients; the role of informed consent in the relationship between consumers/patients and food and medical professionals). Numerous conflicts and controversies on economic, financial, cultural and other issues will arise, inspired by various political and ideological world views.

In the following chapters, we include analysis of these developments and make constructive proposals for the interfaces both from a procedural perspective (emphasizing the necessity of new participatory organizational relationships in these grey zones) and a substantive perspective (emphasizing the necessity of embedding individual autonomy in sociocultural contexts). In chapter three and four we take a fresh look at the current definitions of the problem of obesity and assess these definitions by not only taking into account the usual ones, but also heterodox definitions of obesity. Our endeavour is, as we said, focussed on better problems, not only on

better solutions and therefore we allow us to whittle question marks into the daggers of insight given by the usual experts.

Part II is devoted to the study of several concepts of obesity and investigates the relation of obesity with social issues like responsibility. In the third chapter, *From gluttony to obesity*, we delineate three main constellations managing obesity before the introduction of genomics. The first, Behaviour, concentrates on behavioural control by the individual (like lining and weight control through Slimfast), with emphasis on individual responsibility and an important role for dieticians. The second, Social Environment, emphasizes the encouraging or disencouraging influence of the social environment on obesity, like the lack of stairs and of healthy food. Here the emphasis is on collective responsibility with a large role for engineers and the food industry. The third one, Body, assumes the determining role of bodily processes, like certain genes or hormones that cause excessive hunger feelings. Surgeons and other medical experts have a large role to play. The core question with respect to the impact of genomics is, will there emerge a new combination of all three constellations or will there happen something totally different; this question will be raised in the fourth and later chapters.

The fourth chapter, *Contesting the obesity 'epidemic': elements of a counter discourse*, consists of the second step of analyzing the framing of obesity, by showing that lots of findings with respect to obesity are controversial. In the chapter claims are discussed concerning the health risks and counter claims regarding the insufficiency of medical knowledge in particular from the side of organisations of obese persons. We will show how these counterclaims cool the talk of an epidemics a bit but do make the risks plausible enough to be interesting and worthwhile to philosophize about genomics and obesity. It turns out, because the search for medical solutions of obesity is the trillion dollar thing, that many scientists are exaggerating the risks and costs. Furthermore, we show that each of the main constellations, behaviour, environment, and body, have their own counterpart in three counter constellations, in 'fat is beautiful', 'it is the environment, stupid!', and 'it is only our genes'.

The fifth chapter offers an analysis of the relationship between genomics and obesity both in the present situation and in the near future. The four developments of genomics, i.e., developments of prevention, of individualization, of new risks and uncertainties, and of information management, connected with the three constellations towards obesity, give different outcomes. We show that the preventive instead of curative swift, the individualizing in stead of collective trend, new types of risk perceptions for a healthy life and the new issues of selection and management of information pose considerable ethical challenges, and give the second and third constellation a new boost: genomics favours the interaction with environments and with genetic make-ups.

Chapter 6 covers the relationship between genomics, obesity and responsibilities on the basis of the four trends. In all the constellations, responsibilities play a different role, be it individual (in behaviour), collective (in environment) or a mix if the two (in body). However, responsibility according the pragmatist outlook emphasizes retrospective and prospective responsibility and accountability. The struggle over

responsibilities, and the blaming game between the three constellations, should be seen in that light. We will stress that responsibility in itself has no direct implications for a blaming game or putting on trial people or structures. Instead, we discuss the role of the various stakeholders like the role of fast-food industry and the function of practices of the three constellations on the basis of new accountability structures.

Part III offers an exploration of various futures of genomics, the different scripts of genetic testing and the blurring of distinctions between health and disease. In Chapter 7, *Obesity in 2020. Three Scenarios on Techno-socio-ethical Co-evolution* several futures of genomics applied to obesity are delineated with different directions. Two important issues are discussed, i.e., the current phenomenon of testing and the implications of the disappearance of the distinction between health, functioning well and disease. The chapter develops a tool of pragmatist ethics by outlining three scenarios with the help of which we make a comparison between the three already established discourses. Prevention, individualization, new risks and uncertainties about the possibilities of a genomics cure for obesity and data management play a role.

Chapter 8 focuses on one aspect of genomics services and products and discusses the direct-to-consumer genetic testing and it poses questions like: What do new screening possibilities imply for the struggle over responsibilities? Are the promises: individual, tailor-made advice, realizable? Is the future individualized medicine? Is this a self-destroying prophecy?

In Chapter 9, Maartje Schermer tackles the issue of enhancement medicine/cosmetic and the growing overlap of enhancement medicine and cosmetic medicine/industry. She concludes that for many ethical issues, the demarcation between the health and the aesthetic perspective is important, but it is also clear that this is a contested and not always clear division. Health and aesthetic considerations do sometimes overlap or coincide, but can also diverge. Moreover, the developments in genomics may change the health and aesthetic perspectives, as well as their mutual relationship. Genomics research will give us many new powers to intervene in the human body as well as to change (public) perceptions and attitudes towards obesity and overweight; however these powers are not easily to identify and even often impossible to predict and might go in many directions.

In Part IV we present a tripartite comparative study with the aim to analyse how obesity, health and food are framed and managed in two different countries and what the chances are for a genomics innovation strategy for a happy co-evolution. Chapter 10, *Obesity and Genomics in the Netherlands*, offers an overview of the Dutch general situation and of the policy of the main stakeholders (including organisations of obese persons) on these issues. Next, Chapter 11, *Obesity and Genomics in Italy,* offers an overview of the situation in Italy and presents the result of a workshop with Italian experts on this issue. Finally, as the last chapter of the comparative trio, in Chapter 12, *Holland-Italy: a match too far?,* a comparative analysis is undertaken to show how different cultural and social frameworks frame the leading concepts and policies in the two countries. With respect to the selection of stakeholders that participate in formulating the policies of Netherlands and Italy, the approach of overweight and obesity, and the concrete applications we will show

the similarities and differences between the Dutch and the Italian approach. We ask moreover in how far the four trends are present in Italy, which of the three constellations (or others!) tackling obesity are at present dominant and what the value of the future scenarios is for Italy. It gives a refreshing look into the peculiarities of the European experiences, the varying framing of leading concepts and the varying co-evolution of obesity and genomics.

In Part V, the three chapters cover subjects that in the course of considering the relationship between genomics, obesity and social institutions and ethical values have presented themselves as quite urgent. It is therefore called Food and Health: Toward a happy Match of Genomics, Obesity and Values. Chapter 13, *Public and Personalized Health*, presents an analysis what nutrigenomics, the study of the interactions of diets and genetic profiles, can mean for the distinction between health and food and for the balance between public and personalized health, in particular directed in preventing obesity. Moreover, it is argued that nutrigenomics is faced with myriad ambiguities and uncertainties (e.g. scenarios of varying futures, uncertainty about the possibility of a cure and uncertainty about the relationship between genetic profiles, organisms and environmental factors like food intake and life style). When nutrigenomics is applied in forms of personalized nutrition in preventing or reducing overweight and obesity three types of ethical concern emerge. The first concern covers the relationship between food and health, the second issue is that of the relations between personalized and public health nutrition and the third covers ethical issues of making use of personalized nutrition and its concomitant vicissitudes (to be dealt with in Chapter 15). These three main issues are mostly approached from the utilitarian perspective of individual autonomy (informed consent or informed choice). In the chapter the new grey zones between food and health are discussed when food becomes preventive medicine, just as the shifting responsibilities between public and private actors.

Chapter 14, *Expectations and disappointments regarding the human genome. The genomics health card and anti obesity-pills* is devoted to various hypes and trends nutrigenomics has been subjected to. It turns out that in the development of a science, like that of genomics, (utopian) promises play a mobilizing role, what can be called organized utopianism, and which are alternated by the more common known phenomenon of organized scepticism, in which criticism and modesty prevail. However, for people who sincerely expect innovations of genomics (be it services, products or insights) these disillusions can be discomforting.

Chapter 15, *Matching Nutrigenomics, Society and Values*, relates the different vocabularies of nutrigenomics (including applications like testing practices) with the hypes and trends implied by the current and potential state of affairs regarding nutrigenomics. We discuss several theoretical approaches towards these vicissitudes, and propose an approach of co-evolution in which genomics developments, social institutional and ethical development reciprocally influence, stimulate and inspire each other.

In the concluding Part VI and Chapter 16, *Beyond obesity: social ethical aspects of genomics*, we discuss the ethics of shifting responsibilities from the personal, collective and social dimensions and transform the four trends of the current state

of nutrigenomics from our second chapter in paradoxes. The preventive drive of genomics, its individualizing tendencies, the emergence of new risks perceptions and the increase of data management regimes turn into their counterpart when taken seriously. A happier match between genomics, society and values is recommended on the basis of the concept of fair representation. This proposal can one step in the direction of answering the question, how to feed and medicine oneself as a (potential) obese person in a technological culture in which in particular genomics is permeated by so many vicissitudes and new risks.

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Chapter 2
Genomics and Obesity from a Pragmatist Point of View

Michiel Korthals

Introduction

An ethical study like this on the relationship between genomics, society and obesity requires a clear perspective, one that does not work as a barrier to new insights but rather provides a guideline for identifying new aspects. In this chapter we discuss our perspective generally in the first section, then give an overview of genomics and obesity, next discuss the main trends that we want to explore in this study and finally present ideas what pragmatism can mean in relation to genomics and obesity. We will in the last section explain on the base of these considerations the overall structure of the book.

Pragmatism

The pragmatist approach in philosophy has a shorter history than other philosophical strands, but nevertheless shows considerable variation. It all started in the USA during the 1860s and 1870s, when Charles Sanders Peirce, who was influenced by continental philosophers such as Kant and Hegel, approached thought, language and meaning in a new way. William James, originally a medical student, developed this approach to psychological and epistemological issues in the 1890s, and William Dewey (1859–1952) synthesized their views in his long life due to his broad interests in not only psychology, but also in more social, political and educational areas. Others, such as George Herbert Mead and William Baldwin, performed important research on social and psychological issues. This research is well documented in H. S. Thayer's outstanding book *Meaning and Action* (1981).

The ethics of pragmatism, if one may say so, were primarily developed by Dewey, who elaborated on the ideas of James and Baldwin, who in turn were inspired by Kant and Darwin. In 1897, James stated in *The Will to Believe and*

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Other Essays that the highest moral activity was that which would make 'for the best whole'.

> Let us seek, he urged, the victory of . . . the more inclusive side, – of the side which even in the hour of triumph will to some degree do justice to the ideals in which the vanquished party's interests lay. The course of history is nothing but the story of men's struggles from generation to generation to find the more and more inclusive order. Invent some manner of realizing your own ideals which also satisfy the alien demands, that and that only is the path of peace! (James, 1897, 205)

In other words, inclusion is what a pragmatist ethicist should strive for.

Our approach is also inspired by Deweyan ethics, so it is worthwhile to consider his main ideas. Dewey's main motivation consisted of the harmonization between what is real or seems to be real and what is aspired to.

> The problem of restoring integration and co-operation between men's belief about the world in which he lives and his believes about values and purposes that should direct his conduct is the deepest problem of any philosophy that is not isolated from life. (*Quest for Certainty*, 1960, 255–256).
>
> A moral situation is one in which judgment and choice are required antecedently to overt action. The practical meaning of the situation – that is to say the action – is not self evident. It has to be searched for. There are conflicting desires and alternative apparent goods. What is needed is to find the right course of action, the right good. . .. Ethics is there for a form of inquiry; it doesn't consist in simply applying fixed standards. Ethics is 'inquiry in intelligence'. 'The process of growth, of improvement and progress, rather than the static outcome and result, becomes the significant thing.' (*Quest for Certainty*, 1960, 255–256)

In this study we continue in the same vein as that which formed the basis of our 2002 work on pragmatist ethics, *Pragmatist Ethics for a Technological Culture*, in which we introduced a modified concept of practice and several methods (instruments) for identifying, framing and coping with social and ethical issues. This approach enables us to concentrate on emerging practices, new moral norms and new ways of being accountable. New concepts and tools introduced in earlier publications– such as transcending dichotomies, translation of fruitful solutions from one field to another, finding common ground and future scenarios – can be used in building the trustworthy institutions that will have to emerge in these new interfaces between genomics and society and that need checks and balances between producers and consumers (Keulartz et al., 2002). This new theoretical framework allows us to analyse the interplay or co-evolution between technological, social and normative developments, thus determining the dynamics within and between food and health care practices.

Genomics

Seen from the viewpoint of pragmatist ethics, genomics as a new branch of science and technology covers many potentialities, dilemmas and risks. However, because of the newness of this field, these aspects are not easy to delineate. Therefore, we first have to dive into genomics and try to formulate better questions rather than immediately trying to give answers.

Genomics emphasizes the functional status of genes, proteins and metabolites. Long-term influences of nutrition and, indirectly, lifestyle elements become important (Brudnak, 2001). In genetics, a one-to-one determinism between a gene and a trait (protein) was traditionally assumed. In genomics, however, there is not supposed to be a one-to-one gene determinism; genes code for proteins, but in a polymorphic way, and the proteins themselves interact in complexes and so-called molecular machines. Moreover, proteins or their complexes can turn genes on or off. In the definition used here, genomics stands for the entire scientific field, including proteomics and metabolomics. Nutrigenomics is the study of the gene-environmental relationship in the field of nutrition (Kasteren, 2001; Werf et al., 2001). The field of nutrigenomics can be characterized something like this: DNA expresses itself in mRNA, which codes for proteins, which determine metabolism, which determine the dietary intake. But it also works the other way around, and what you eat (the proteins you consume) can have a powerful, long-term influence on which genes will be expressed. Dietary intake influences metabolism, proteins, the expression relationships and the code relationships. To find out exactly how nutrients influence gene regulation and transcription is a huge scientific enterprise, and it could even be an impossible task.

Nutrients not only affect genes that regulate food intake, but also influence appetite, i.e. the desire to eat or not eat and the feeling of satiation. Several proteins determine these feelings, and they are either triggered or silenced by specific nutrients. Think about the fact that when you drink two Cokes you consume as much energy as when you eat a hamburger, although in the latter case you feel much more satisfied. In the case of the hamburger, Leptin, CCK and PYY are much more involved (see Fig. 2.1). Bioactive nutrients are responsible for both typical reactions. Some say that variations in a gene with still unknown functions, the FTO gene, contribute to weight gain. Prof. O'Rahilly assessed the defective FTO gene that results in a continuous feeling of hunger:

> A defective FTO gene is present in 60 percent of the population. Children whose father and mother both have the gene defect are on average three kilos heavier than normal carriers of the FTO gene. Normally, this FTO gene influences the hypothalamus (Lecture on *Lof der Geneeskunst*, Erasmus Medical Centre, Rotterdam 2007).

However, others doubt the role of this gene in the general population of obese people. Probably many genes together, and sometimes in very small fractions, co-determine the final outcome.

One consequence of looking for nutrients that affect genes that are strongly associated with diseases in later life is that the sharp distinction between food and medicine seems to become blurred, and a grey zone emerges between the two. Food acquires characteristics of medicine and determines which kind of medication is necessary. Medicine becomes food or influences food intake. This new grey zone, where health care and food meet, is the battlefield on which new ethical problems are emerging that require solutions through constructive ethical thinking and intensive public debate. With the rise of 'x-omics' disciplines, new practices like screening agencies and databanks are emerging, and old ones, like those mentioned above, are

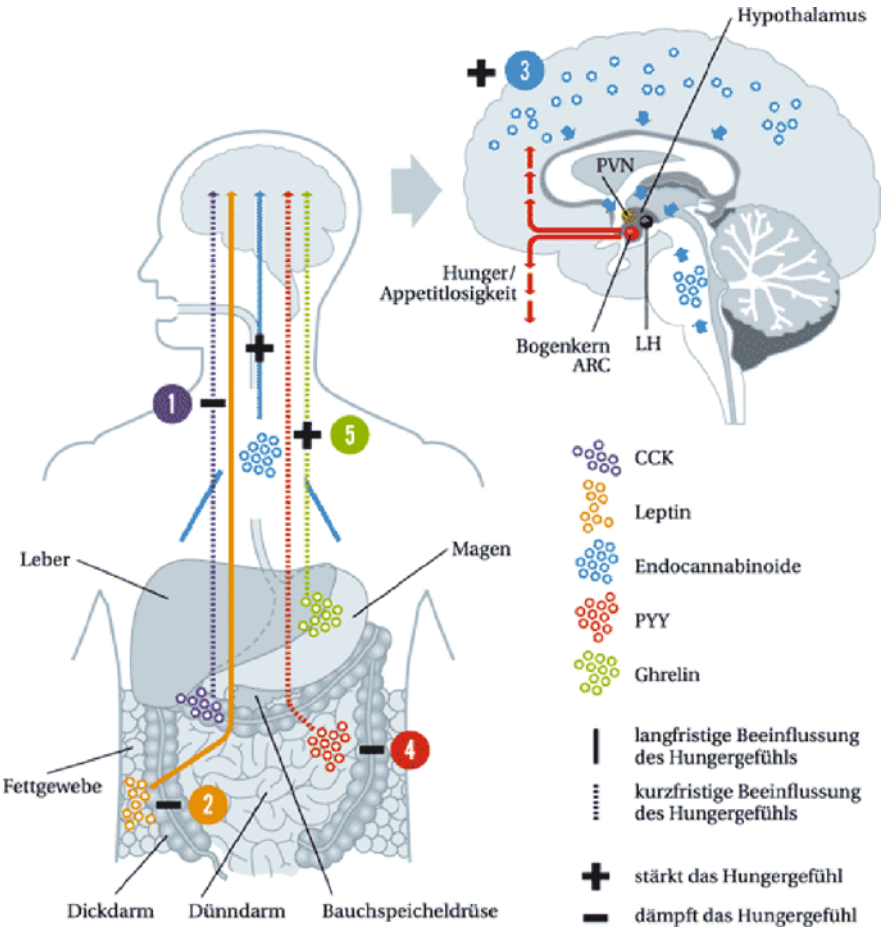

Fig. 2.1 Appetite stimulating and suppressing proteins

being challenged to take into account the new scientific insights and devices. This struggle over tasks and responsibilities still continues.

Obesity

As stated above, nutrigenomics focuses on the pathways via which DNA expresses itself in mRNA, which in turn codes for proteins that determine metabolism, which then determines dietary intake. At several locations on these pathways, obesity and obesity-related issues are addressed. Obesity means that there is an imbalance of energy input and output. Therefore x-omics can assist in diagnosing, preventing and curing obesity wherever genes, proteins, enzymes and hormones play a role: input (intake of food, drugs), storage, and output (exercise). However, these new

disciplines are not the first or only ones to manage obesity. There is a long history of medical and social-psychological approaches to obesity that start with different assumptions about the definition of obesity.

As will be discussed extensively in Chapter 3, there are at least three major existing paradigms that try to manage obesity. The first one is directed towards behaviour, with an orientation to the *individualization* of the problem (typical products: Slimfast and a large role for the dietician). This is generally the paradigm of diet-related sciences, such as social psychology. The second paradigm is directed towards the social environment, with an orientation to *politicalisation* (typical products: stairways and bicycle paths, and a large role for engineers). This is the paradigm of many social and political scientific approaches. The third paradigm is directed towards the body, with an orientation to *biologisation* (typical examples in the sciences are genetics and surgery, which implies a dominant role for medical experts). These three paradigms differ in their emphasis on the various parties involved in handling obesity; they allocate the responsibilities among the stakeholders differently, and attribute blame differently to the parties involved. As is clear from these three paradigms, not only food and drugs are being held accountable for obesity; in the political practice concerning obesity, social actors such as housing agencies and public space engineers are being held responsible as well.

Obesity genomics has a complex message. It is essentially: 'if you don't exercise, and you have SNPs xxxx (=single nucleotide polymorphism, a variation of a common gene), you have a severe risk of obesity, except if you take drug y. If you don't eat fruit, and have SNPs yyyy you can also develop obesity, but not if you can afford drug z.' Both of these lifestyle activities are dependent on social and economic status. This strategy is not directly individualization (first paradigm) or exclusively politicalisation (second paradigm).

For citizens and consumers, the answers to the following questions are not easy, to say the least.

- Who is responsible for the epidemic of obesity?
- Who is responsible for preventing and curing the obese and what kind of measures should be taken?
- Who is responsible for the risks, interferences and dangers connected with the different kinds of preventative measures?
- Who evaluates the outcome?

New moral ideas are necessary with regard to genomics and nutrigenomics; these ideas revise the concepts of individual autonomy, informed consent, equal access to medical resources, equal opportunities, common heritage, what is to be accepted and what is to be changed, and the quality of life in general. Informed personal consent and autonomy are traditionally the keywords in bioethics (O'Neill, 2002; Burgess, 2007). In medical ethics, they were (at least before the beginning of the 21st century) the cornerstones for the negotiations between patients and professionals. In food ethics these concepts have been invoked in regulating (i.e. labelling) genetically modified food in accordance with the concept of consumer sovereignty. In both

medical bioethics and food ethics, however, new technological and socio-practical developments challenge the presuppositions of these concepts, such as the emphasis on individual decision-making, and more generally, the emphasis on procedures that neglect collective, normative and substantive issues of how to live with these new developments and how to manage new collective arrangements like biobanks (Caulfield et al., 2003). The limitations of these individual concepts are becoming clearer, but it is not at all clear which concepts can correct or overcome these limitations.

Four Trends: Prevention, Individualization, New Risks and Information Overload

The new food and health sciences that are emerging in the West are subject to many changes, but there is a general agreement among involved scholars that at least four important trends can be discerned that are specifically driven by the introduction of genomics and nutrigenomics technologies and tools. These introductions are enabling the medical and food sciences to become *preventive* instead of curative, which will have far-reaching effects on future generations. They are also having an *individualizing* effect, by enabling tailor-made individual approaches; they are giving rise to *new kinds of risks and scientific uncertainties* and are producing a huge amount of information (e.g. bio-informatics) to the degree that one can speak of an *information burden*. This will pose challenges to traditional ways of handling information.

These four important trends imply new concepts and attitudes about health and food, and new tasks and responsibilities for the five main stakeholders: medical and food professionals (including scientists, dieticians and family doctors), consumers/patients, government regulators and the general public. In short, they give rise to a great deal of controversy and require new interfaces between these groups.

Prevention requires a long-term perspective from producers as well as consumers (Horstman et al., 1999). Food professionals, for example, have to take into account that the bioactive components that will be integrated into foodstuffs will be eaten for many years; this integration work requires the involvement of consumers in the innovation and design process of food (Dekker et al., 2000).

The tailor-made approach, for example, requires individual screening and monitoring methods, ways of storing information relevant to individuals (such as gene passports), and the creation of individualized recipes. In addition to the possible disciplining effects that could curb individual autonomy, this approach could also overburden individuals by making them responsible for future generations and partners in their immediate and future network. Tailoring is a paradoxical affair; it ostensibly means individualization, due to the individual specification of food and medicine, but the collective implications are huge, such as those for relatives, future generations and even the common genetic heritage of mankind. In this respect, consumers/patients could be confronted with shifting relationships towards their relatives in preparing and consuming meals and changes in their lifestyles in general.

New areas of agreement and/or disagreement between parents and children could emerge. In the case of management of diabetes patients, for example, both trends are already present, but they will show their full force in the case of the implications of genomics and nutrigenomics.

The new risks with respect to health and food require that individuals learn to reflect on the desirability of knowing the risks, and to either do something or not do something about the risks, or decide to not know. For food professionals, this requires the integration of risk-assessment methods like the Bayesian approach in the normative belief systems of patients and consumers (Van Boekel, 2001). The risks are intrinsically connected to uncertainties: known unknowns and even unknown unknowns. The trends themselves are not really known, but more specifically, it is unclear to what extent diagnostics will be followed by corresponding therapies, and to what extent genes determine, influence or affect people's lives.

The huge production of information will require ways of distinguishing between relevant and non-relevant information, between reliable and unreliable information and between consistent and inconsistent information. To make these distinctions, people need new ways of dealing with information, i.e. they need a new concept of agency. Moreover, this agency requires new interfaces between producers and consumers that enable consumers to make up their own minds (Korthals, 2001). It also requires clear objectives to steer the selection, maintenance and access of relevant information, which are often lacking.

A Pragmatist View of Genomics and Nutrigenomics

With respect to genomics and nutrigenomics, the pragmatist approach enables us to concentrate on emerging practices, new moral norms, and new ways of being accountable. The pragmatist concepts and tools introduced in previous publications – such as transcending dichotomies, translating fruitful solutions from one field to another, finding common ground, and creating future scenarios – can be used in contributing to a happy match between genomics, society and values and norms. This match will be a dynamic one, because new interfaces will emerge and they will need checks and balances between producers and consumers (Keulartz et al., 2002).This theoretical framework allows us to analyse the interplay between technological, social and normative developments, to determine the dynamics within and between food and health care practices, and to analyse the implications of the four trends for the various stakeholders. This means that we conceptualize the emergence of genomics and nutrigenomics (and the various medical and food professions) as the creation of responsibilities that cover the entire life span of patients/consumers. The membersof this innovation network, professionals, including dieticians, consultants, physicians and food communicators, all become involved in preventive monitoring, management and intervention in the daily health and food habits of consumers.

Traditional medicine is curative and collective, while traditional food practices imply only the responsibility to produce safe food. With genomics and

nutrigenomics, however, huge shifts in responsibility between the medical and food practices are at stake; the food practices acquire some responsibilities that previously belonged to the medical practices and some responsibilities that are new. The still utopian idea of a gene passport can only be effective as a health compass, recipe provider and menu if it is constantly adapted to new circumstances, such as a new lifestyle or a recently discovered effect of a food product, or new knowledge about the effectiveness of certain food ingredients. This adaptation requires monitoring and diagnostic institutions to keep the gene passport up to date. Many will interpret this to mean that food scientists or professionals want to take control of daily life, and they will raise controversial questions not only about fundamental issues, but also about issues concerning the implementation of a gene passport, for example. What about litigation processes of disabled children or children who require other genetic abilities than those chosen for them by their parents?

From a pragmatist point of view, however, the idea of living and cooperating informally with other people is a serious and substantive value, one that could function as a source of inspiration for food and health professionals in the management of these new tasks, and as a consequence, one that enables them to become conscious of their new responsibilities in shaping the lives of citizens and consumers. By stressing the interfaces between the five groups of stakeholders, we can identify the shifting responsibilities and new tasks of food and medical professionals and consumers alike. All these changes are saturated with the paradox of the socializing consequences of the individualizing, tailor-made approach of genomics and nutrigenomics.

The four trends (prevention, individualization, new risks and information overload) elicit a great deal of controversy that requires new procedures of interaction between stakeholders and a collective reflection on the substantive issue of how to live a good life in this new technological culture. By combining these procedural and substantive levels of reflection, we are able to transcend the often narrow liberal and individualizing presuppositions of a Kantian or Rawlsian approach and can take into account the social networks and embedding of individuals (Korthals, 2001). Even in a future where genomics and nutrigenomics have a dominant role to play in health and food habits and choices, some social and biological circumstances have to be accepted – living a good life in the awareness of what to accept and what not to accept remains crucial. Nevertheless, genomics and nutrigenomics will change the premise of this crucial question.

For professionals, the new responsibilities mean functioning in interfaces and trustworthy institutions that regularly and systematically report on their activities in a lucid and transparent way, and acting in an accountable manner in cases were mistakes are made or uncertainties abound. For consumers/patients and the general public this means asking what the advantages and disadvantages of these technologies are in terms of living a good life.

Criteria of trustworthiness and accountability of institutions that can rely on collective consent and enable individuals to make reasonable decisions on food can be fleshed out by using the two concepts of Hirschman (1970), exit and voice, with

the addition of a third, access, suggested by Korthals (2001). By exit, Hirschman means that people can leave a certain market system without being punished in a material or cultural sense. The right of voice concerns the opportunities consumers should have to raise their voice vis-à-vis the market system and to be able to shape normative or substantive opinions and act accordingly with respect to this market system.

These two rights should be supplemented by a third one: the right of access. This is the right to establish a certain food system on the market that is based on new concepts of food (in fact, this right also concerns actions of producers). Right of access of patients/consumers in the case of nutrigenomics means that, on the basis of the principle of justice, attention is paid to the genetic basis of their diseases and research is done into the interconnection between this basis, the nutritional elements and lifestyles (Buchanan et al., 2000). The right of voice means that genomics and nutrigenomics should not only be accompanied by public debate (Rowe and Frewer, 2000), but also by all kinds of public councils. These councils should be firmly anchored in the various practices of the genomics and nutrigenomics system that enable stakeholders to be held accountable and to raise the substantive issues of how to integrate genomics and nutrigenomics improvements in human life. The substantive issues in these processes of accountability are not only the risks to human health and the environment. They also concern the way animals, plants, and farmers are treated and how lifestyles are respected, including the lifestyle that wants to stay aloof from genomics and nutrigenomics. The right of exit would mean that consumers could quit the nutrigenomics system and choose, for example, to not be informed about certain risks they might have for developing a genetically based disease, and as a consequence, could ask their social environment to respect this right to non-information.

Access, voice and exit acquire their full meaning from the debate on regulatory and substantive issues. Moreover, voice, access and exit are shaped differently depending on local culture. But this collective dimension does not mean that a culture should give its consent: it is still individual consent for a social heritage (more about this in Chapters 15 and 16).

Implications for the Pragmatist Study of Genomics and Obesity

Crucial to the pragmatist ethical analysis of the problem of obesity is the definition of this problem. In the current literature, this definition is very often given in a casual way by directly copying the established definition. The argument then moves on to give some outlook about the risks obese persons face, and subsequently addresses solutions. The Body Mass Index is mentioned, and perhaps another measure, like the belt index, but that is all. However, there is considerable disagreement on some aspects of obesity; for example, to what extent it really is an illness and whether obesity can indeed be defined in a relevant sense as the simple imbalance between

input and output of energy. From a pragmatist approach it is necessary to analyze the existing battlefield of obesity, including the main stakeholders, the main paradigms, practices, controversies and the main interests.

One can discern at least nine groups of stakeholders. These include:

- obese individuals, who are often organized in shared interest and self-help groups, sometimes connected with other patients groups;
- potential obese individuals, i.e. consumers who have overweight or run the risk to become obese;
- medical professionals, including general practitioners involved in primary health care and specialists who deal with more serious problems such as diabetes II, cardiovascular disease or people wanting cosmetic surgery;
- the diet industry;
- the food industry;
- the lifestyle sector, comprising the PC, mobile phone, game and video branches;
- governments (national and international);
- insurance companies;
- retailers.

In accordance with this approach, we take several steps in this study to define the problem as clearly as possible. After defining the problem, we work on it in several phases. First an analysis step is taken, then a constructive step, and finally we look for the implications of these steps, also by comparing different national approaches to obesity and genomics. The analysis step covers three phases.

In this book, we start in Chapter 3 by analyzing the existing battlefield of obesity and categorizing the main perspectives or discourses. Then in Chapter 4 we summarize the counterarguments and counter-practices that do not fit into the dominant discourse. In Chapter 5 (the second, constructive, step) we discuss what the relationship between genomics and obesity can imply from a pragmatist point of view. In Chapter 6, we go more thoroughly into the ethical issue of responsibility and we try to find out what should be done by whom and why. In Chapter 7 (the third step of looking for implications and developing more specific ethical results) we first develop a tool to get a clearer picture of the future responsibilities and possible trajectories by providing scenarios. We then discuss two effects to which genomics makes an important contribution, and which are already underway: testing and screening, (Chapter 8) and enhancement (Chapter 9). This is followed by an international comparative analysis of these issues that results in an outline of the different cultural frameworks that underlie the national strategies to match genomics with obesity, society and values (Chapters 10, 11, and 12). In the final three chapters we discuss the ethical implications of obesity genomics for the distinction between public and private health, the distinction between health and food (Chapter 13), the hypes and trends of nutrigenomics (Chapter 14) and the meaning and management of these different vocabularies and vicissitudes (Chapter 15). Finally, we offer conclusions and reflections on our original intuitions, some provisional solutions and an outlook (Chapter 16).

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Part II
Concepts of Genomics and Obesity; What Can Genomics Imply for Society?

Chapter 3
Behaviour, Environment or Body: Three Discourses on Obesity

Tsjalling Swierstra

Introduction

To this present day, assessing the ethical, legal and social implications of genomics is by and large assessing the future. Most of the implications of genomics have yet to manifest them selves. How will society be affected by applications of genomics to obesity, medicine and food? How will ethics be affected? To start answering these questions we cannot but begin in the present. The society we belong to forms the cradle of the new genomics and the medium in which the implications of genomics will manifest themselves. Existing social, cultural, moral and economic constellations co-determine the shape, speed and direction of future technological developments. On the other hand, a new technology can be expected to reshuffle current ideas, practices, institutions, and discourses. Technology and society co-evolve. This co-evolution also holds for the introduction of genomics in society.

It is important to stress that society is a heterogeneous whole. Strife and controversy are always to be expected. This is particularly true in the case of new technologies that uproot deep-held convictions and well-established practices. The current 'hypes' en 'horrors' surrounding genomics are a case in point. From a methodological point of view this means that to assess the implications of genomics, one first has to describe the rifts and ruptures that can be expected to influence the ways genomics will eventually be socially embedded. Of course, one cannot do this in general terms. So many controversies might affect the eventual embedding of genomics, that it is impossible to map them all at forehand. But it is possible to map the controversies pertaining to the topic of this book: genomics and obesity.

In this chapter, we will investigate three rivalling discourses that currently dominate the debates on obesity in the West. These discourses ascribe a specific meaning to obesity, point out causes, remedies and responsible actors, lay down the rules for what can be said and what cannot. Discourses are not simply factual descriptions of existing states of affairs. They have a practical point in so far as their diagnoses locate responsibilities and accountabilities, and indicate the direction for

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finding solutions to this problem. All three agree that obesity constitutes a pressing problem, but then continue by focusing on different causes of and solutions to this problem. The first discourse centers around individual actions (behaviour), the second gives centre stage to environmental influences, and the third discourse focuses on biological causes in the body. As a result, discourse I individualizes and moralizes; discourse II moralizes but does not individualize; and discourse III finally individualizes but does not moralize.

Discourse I: Behaviour – Individualizing and Moralizing

Obesity has for a very long time been considered an important *moral* problem, long before it was considered to be a *medical* problem. Since the ancient Greeks, obesity was deemed to be the sure sign of a lack of self-control. Weakness of will (akrasia) is the most important category that ethical theory offers us to understand obesity (Gosling, 1990; Ainslie, 2001). Weakness of the will is understood as knowing that one ought to do something, but not being able to carry out this course of action. For example, Aristotle in his *Nicomachean ethics* (=NE, 1982) states: 'But there is a person who abandons his choice, against right principle, under the influence of passion, who is mastered by passion sufficiently for him not to act in accordance with the right principle, but not so completely as to be of such a character as to believe that the reckless pursuit of pleasure is right. This is the unrestrained man: he is better than the profligate, and not absolutely bad, for in him the highest part of man, the fundamental principle, is still preserved'. (NE, 421). Eating without moderation is a typical instance of akrasia. 'Now you can have an excess of the bodily goods; and it is pursuing this excess that makes a bad man, not pursuing the necessary pleasures, for everybody enjoys savoury food, wine, and sexual pleasure in some degree, though not everybody to the right degree' (NE, 443) An obese person is someone who is a 'slave' to his passions, and therefore not really free and virtuous.

In Christian morality, bodyweight becomes even more of a moral problem because now it acquires a religious meaning. Compared to the ancients, the Christian, ascetic condemnation of *all* bodily pleasures – instead of only an excess of them – was new and radical. Gluttony was one of the seven mortal sins of Christian morality, directly conflicting with its supreme command: obedience to God. The apostle Paul (3–67) wrote about it in his letter to the Philippians: 'For, as I have often told you before and now say again even with tears, many live as enemies of the cross of Christ. Their destiny is destruction, their god is their stomach, and their glory is in their shame. Their mind is on earthly things.' (Phil. 3, 18–19). One finds a similar denunciation in Geoffrey Chaucer's (1343–1400) *The Canterbury Tales*: 'Gluttony is immoderate appetite to eat or to drink, or else to yield to the immoderate desire to eat or drink. This sin corrupted this entire world, as is well shown by the sin of Adam and Eve. [. . .] He that is addicted to this sin of gluttony may withstand no other sin' (see Oksenberg-Rorty, 2001, 105). Similarly, John Milton (1608–1674) writes in *A Maske* (or *Comus*): 'Swinish gluttony, Ne'er looks to heav'n amidst his gorgeous feast, But with besotted base ingratitude, Crams, and blasphemes his

feeder'. (line 776.) Gluttony is a sin according to Milton because it distract from the vertical relationship with God the creator. Key element of these virtue-ethical condemnations is that the obese person him/herself is the sole stakeholder. In the end it is only his/her health/life/soul that are at stake (Korthals, 2004).

The basic concept that obesity is a sign of an inability to control the bodily passions by our ratio or by our devotion to God is not limited to the past. The Italian-German food philosopher Francesca Rigotti states in a similar vein in her *Philosophie in der Küche* (2002) that eating too much is similar to talking too much. In both cases the vice of excess is at stake. To our day obese people are often judged, ridiculed, despised and ostracised. There exists a pervasive norm that we should all make the most of ourselves. Obesity is a 'biomarker' that one fails to do so; it indicates a lack of character. Jennifer Crocker, a social psychologist at the University of Michigan, has shown how obesity is often considered to be one's personal fault and failure, even by the obese person him/herself who for this reason often suffers from low self-esteem.[1]

However, in our time such moral condemnations have become less overt. At the background of this a-moralisation of being overweight lay the general marginalisation of virtue-ethics and the secularisation that characterise modern liberalism. Conceptions of the good life and our supposed obligations to God are in modern, liberal and pluralistic democracies increasingly considered to be private matters. There exists a marked uneasiness with openly moralizing about another's life-style. If this life-style is the outcome of someone's free, autonomous choice and if it does not harm others, we are expected to keep our opinion mostly to ourselves. Judging other people's lifestyle is dismissed as paternalistic. The thin and secular morality that rules the public sphere in modern Western societies lacks the concepts to morally denounce obesity.

Does this mean that the society no longer frowns upon obesity? Of course not. On every billboard, on every TV-show our culture emanates that one should be mean and lean. The women populating the paintings of Rubens would by current standards be dismissed as far too fat. Youthful and thin bodies are the norm. Pushing this trend to an extreme, fashion photography even experimented with the so-called junky-look, and each year the models look younger and thinner. The *moral* condemnation of being overweight has been replaced by an *aesthetic* one that is equally coercive and suppressive in practice. These aesthetic condemnations are the perverted heirs to the antique and Christian forms of virtue-ethics.

The interesting contrast between ancient and Christian attributions of meaning to obesity and modern ones is that the core message is no longer a plea for self-restraint, but for *effortless* youthfulness. Be thin *and* party!! This is not so deny that millions of people are working hard to control their weight. The point is that this hard work hardly warrants them extra moral points. Their results look bleak if compared to the real thing: effortless thinness. (Compare this to having a face-lift. The result can only approach the real thing.) Now the solution to obesity no longer officially requires an effort on the part of the individual, as in the virtue-ethical

[1] Cited in the Dutch journal NRC,: www.nrc.nl/W2/Lab/Profiel/Overgewicht/psyche.html

approach, such a solution can now legitimately be bought and consumed. Or so the advertisements tell us. A healthy weight is presented as a commodity to be purchased, instead of earned.

But in recent years a double shift in Discourse I can be detected: obesity has first become *medicalised* and subsequently *re-moralised*. A host of articles and government reports point out that obesity causes health problems. In itself, excess body weight may not be an illness, but it is believed to lead to medical problems in the short run (among others: arthritis as a result of overtaxing the joints) and long run (diabetes 2, hypertension and cardiovascular diseases). This medicalisation paves the way for a re-moralisation of bodyweight in three ways. First, as a medical problem, obesity is bound to lead to (direct) medical costs. In so far as in western societies these costs are paid by the collective, one could argue that the obesity of the one harms the others. At that moment obesity stops being an individual lifestyle choice, and enters the domain of inter-human relations ruled by thin morality (De Beaufort, 2002, 325ff). Secondly, obesity results in indirect economic costs for society at large in terms of reduced productivity caused by absence, payments for not able to work and the costs of a shortened life-span (Shin-Yi et al., 2004). Thirdly, some condemn it as immoral that the Western, affluent societies suffer from obesity, whereas people in the Third World are still starving (although obesity is increasing there fast).

This re-moralisation is restricted by one important condition. Individuals can only be held responsible for their own weight when they were adequately informed about their food. If not, their choices were not really autonomous. As in medical practice, in questions related to food the principle of *informed consent* plays a role. However, the adherents of this first Discourse hold that every adult in Western societies can be supposed to be aware of the two basic requirements for a healthy weight: healthy food and exercise. This was put forward by the judge in a lawsuit against McDonald's: 'If a person knows or should know that eating copious orders of super sized McDonald's products is unhealthy and may result in weight gain, it is not the place of the law to protect them from their own excesses'. (Weiser, 2003)

To sum up: Although the exact content and background of the condemnation of excess body weight has changed over the centuries, the condemnation itself is fairly constant. At the core of Discourse I. lays the contention that excess body weight is the individual's fault. Obesity is blameworthy, and the blame is squarely laid down at the individual's doorstep. However, there is an important positive promise connected to this strategy of blaming the individual: if obesity is the fault of the individual, this same individual has the power to mend his/her ways and tackle the problem. Redemption is a matter of changing one's ways, of being a little tougher on one self, of work, or of buying the right products.

Now, although this individualizing and moralizing discourse is very influential, it *is* contested. Some deny that excess body weight is a matter of free will, pointing to either the influence of the (economic, social, cultural, technological, etcetera) environment, or to biological causes of body weight. In both cases obesity gets removed from the domain of individual responsibility. We will turn to these two rivalling discourses later. Here we want to point out that also *within* the parameters of discourse I counter-discourses exist. (Compare Chapter 4 by Van den Belt in this volume.)

First, some attach positive meanings to weight: cheerfulness, an attractive sense of spontaneity, being not stuck-up and tight assed, working-class pride (cf. Homer Simpson). Instead of being a sign of immorality and weakness, being overweight is positively re-labelled as something to be proud of, as a sign of *savoir vivre*. Also it has been pointed out that some are attracted to heavier people. From a feminist perspective the dominant discourse on weight has been accused of being sexist and oppressive to women. Nice pictorial examples of these criticisms are the advertisements where Barbie is portrayed as rather plump (in a campaign by the Body Shop) or middle-aged (in the *Volkskrant Magazine* of 28-06-03).

Secondly, doubt has been cast on the scientific evidence sustaining the claims that obesity leads to *medical* problems and that dieting and exercising always enhance one's health-prospects. In the Netherlands the 'Beweging van Formaat' ('The Formidable Movement'), a lobby group for heavy people, has made itself the advocate of this scepticism. Even if there would be a relation between obesity and certain diseases, this would not necessarily mean that these are the result of obesity. Obesity might be as much a symptom of an underlying affliction. Doubt is cast on the efficacy of the dieting and exercising. Evidence shows that dieting itself is relatively unproductive (in some cases even counterproductive). There is the so-called yoyo effect and the fact that dieting people sometimes start to eat more! Furthermore, the dieting that is supposed to reduce medical risks might in fact increase these risks. For these reasons, some professionals are wary or careful in advising dieting.[2]

Another attack on the medicalisation of weight is directed at the idea of a healthy weight itself. This idea presupposes an objective norm or standard. But maybe such a norm does not exist. In that case, we should accept that individuals have 'their own natural weight'. This is the opinion of American food scientist James Hill. 'Thin fat people' he calls the members of his 'research population' who managed to lose thirty or so kilos and now conform to the standard set by the BMI. He thinks of them as 'anorectics with a normal weight'. Dutch food scientist Jaap Seidell calls people like these 'post-obese' and he qualifies them as obsessive.[3]

Thirdly, even if one accepts the aesthetic denunciation and the medicalisation of obesity, this does not necessarily entail the re-moralisation of the issue. It has been argued that although obesity is unhealthy, this does not mean that an obese individual will raise more medical costs than a healthy one. Obese persons die younger, so on the whole they may be cheaper. If that is true, one is not harming one's fellows by being obese, and therefore obesity is not a moral issue. Some also argue that although obesity does lead to extra medical costs, a policy that tries to tax, fine, forbid or punish obesity will be even more morally reprehensible because it would severely invade the private sphere of individuals. If we value our privacy, we should accept that our fellows raise collective medical costs by living unhealthy lives.

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[2] See, for example: NRC, W&O, 20/4/03, 41: The diet of the therapist.

[3] The opinions of Hill and Seidell can be found (in Dutch) at: www.nrc/W2/lab/profiel/overgewicht/lijnen.html

These criticisms remain part of the individualizing and moralizing Discourse, in so far that their focus remains on the individual, and his will, actions and morals. The following Discourses II and III. These contest the key-elements of the previous Discourse: the environment-Discourse attacks the individualizing aspect of the first Discourse, the gene-Discourse attacks the moralizing aspect thereof.

Discourse II: The Environment – Politicising and not Individualizing

The next two Discourses arise from the (perceived) inadequacies of the first and oldest one. Discourse II diminishes the responsibility of the individual by pointing to the decisive influence of the environment. A quite recent WHO-report for example heavily stresses that we all live in 'obesogenic' environments. WHO, 2003). This discourse first of all rests on a pragmatist acknowledgement that the individualizing and moralizing approach simply does not work very well. The scale of the weight problem is expanding in the developed world and in some developing areas as well. Furthermore, the hypothesis of the weak will lacks explanatory power, because people do have enough willpower in many other areas of life: they generally do not steal or kill, and they seem to be able to set and realize life targets. Instead of assuming that in modern times people have become less virtuous and responsible, it seems reasonable to look for different explanations. According to the advocates of discourse II changes in the environment can account for this increase of obesity (Jackson, 2003).

In sociological terms: Discourse II attributes the individual less (deliberate) *acting*, and more (routine) *behaviour*. The individual does not act so much, but is much more often pushed and pulled by *environmental factors*. For instance, a recent report from 2003 (Food Standard Agency, 2003) documents the influence of *commercials* directed at children. The majority of these commercials deal with fast food and sweets. Not one promotes healthy and recommended food like fruit, vegetables or fish. Similarly, where fast food corporations sponsor sport canteens or schools, the children are not stimulated to eat their vegetables. Apart from commercials, information can also be unintentionally misleading. In the seventies the food sciences for example advised everyone to use more vegetable oils, without discrimination. This advice has contributed considerably to the weight-problem because some vegetable oils, like palm oil and palm kernel oil, are implicated in insulin resistance and raise the bad cholesterol (Critser, 2003) And what about the dieticians, who keep raising false hopes and selling ineffective aids even now we know that most diets have no results in the long run? Individuals often lack the necessary knowledge to make informed and healthy choices due to influences beyond their grasp.

On another level, protagonists of Discourse II often point out that being overweight occurs significantly more often among the lower income groups. Although this is partly due to having less access to relevant knowledge, another important factor is the poor quality of cheap (junk) food. It can be considered a form of social deprivation if one is forced to live in places where you cannot buy fresh vegetables and fruits (Stronks and Hulshof 2001). Social deprivation can also acquire an ethnic

character. Although Turkish and Moroccan women and children in the Netherlands eat healthier than their ethnic-Dutch counterparts, they suffer more weight problems. Probably this is caused by their relative lack of physical exercise that is the consequence of their being more often confined to the house.

The infrastructure of modern society has other features that stimulate obesity, like the sedentary life style and the increasing delegation of physical exercise to technology. From agricultural and industrial society to post-industrial society, physical exercise is more and more expelled from daily life and the workplace. PCs for example compel us to stay put, cell phones relieve us from walking to a stationery phone, and elevators help us avoid the steps. Labour saving gizmos like these may seem innocent enough, but together they contribute considerably to the weight problem. Technology considerably contributes to our obesogenic environment (for an overview, Swinburn et al., 1999).

So, there are many environmental factors that mitigate or diminish the accountability of obese individuals. This is not to say that within the parameters of Discourse II *no one* can be held responsible. Protagonists of this discourse link obesity directly to the behaviour and responsibility of corporate actors like employers or the producers and sellers of (junk)food. Food industries are often accused of contributing to obesity. According to Marion Nestlé (2002; no family!), it is in their interest to produce and sell as much food as possible, and to encourage people to eat more. So in the course of the last decades the amount of fat and salt in food products has steadily been increased. The recent row about the industry influencing recommendations of the World Health Organisation adds evidence to Nestlé's accusation. Larger portions, super sizing of drinks, free refill, are some of strategies these industries employ to have people eat more. Offering catering contracts to schools is another strategy.

This tendency to hold corporate actors responsible for the weight problem, has also taken a legal form. For example, MacDonald's was sued both in the UK and in the US. In the UK case it was argued that McDonald's deliberately misinformed its consumers. (Appleson, 2002; Vulliamy, 2002) The company asserted that Big Macs and other products were healthy and nutritious and intentionally concealed information about nutritional value and about health effects of continuing consumption.

> McDonald's try to show in their "Nutrition Guide" (which is full of impressive-looking but really quite irrelevant facts & figures) that mass-produced hamburgers, chips, colas, milkshakes, etc., are a useful and nutritious part of any diet. What they don't make clear is that a diet high in fat, sugar, animal products and salt (sodium), and low in fibre, vitamins and minerals – which describes an average McDonald's meal – is linked with cancers of the breast and bowel, and heart disease. This is accepted medical fact, not a cranky theory. Every year in Britain, heart disease alone causes about 180,000 deaths. (Pamphlet, 1986) (www.mcspotlight.org)

Since these lawsuits, the accusations have even got more vehement. Critics have pointed out that there is some scientific evidence that food rich in sugar and salt produces changes in the brain. The result is that its consumers literally become *addicted* to junk-food. McDonalds: friendly clown or evil drugs-pusher?

Discourse II downplays the role of the individual by pointing to the decisive influence of the environment. The aforementioned WHO-Report from 2003 sums up this position:

> Individual change is more likely to be facilitated and sustained if the macroenvironment and microenvironment within which choices are made support options perceived to be both healthy and rewarding. Food systems, marketing patterns and personal lifestyles should evolve in ways that make it easier for people to live healthier lives, and to choose the kinds of food that bring them the greatest health benefits. An enabling environment encompasses a wide frame of reference, from the environment at school, in the workplace and in the community, to transport policies, urban design policies, and the availability of a healthy diet. Furthermore, it requires supportive legislative, regulatory and fiscal policies to be in place. Unless there is an enabling context, the potential for change will be minimal. The ideal is an environment that not only promotes but also supports and protects healthy living, making it possible, for example, to bicycle or walk to work or school, to buy fresh fruits and vegetables, and eat and work in smoke-free rooms. (WHO, 2003, 138)

It is this environment that should be held (to a large extent) responsible for individual behaviour. The environment is the sum of anonymous forces and the deliberate actions of other (corporate, collective) actors. This means that drawing attention to the environment allocates responsibility differently when compared to Discourse I. In the case of clearly identifiable suspects like McDonald's it is possible to try to make them bear the responsibility by way of a lawsuit. However, this is more often than not impracticable. Therefore, Discourse II routinely makes the state responsible for changing the environmental factors. After all, in most developed countries the state is held co-responsible for the health of its citizens and for the economic well being of the nation – which is threatened by an epidemic of obesity. The *moralisation* of obesity in Discourse I is thus mirrored in the *politisation* (and juridification, as part of that) of this issue in Discourse II: the government should facilitate cycling and sports, make sure that good food is available for lower income-groups, educate the citizens about the dangers of bad food/overeating/lack of exercise, maybe force architects to design buildings that make their inhabitants take the stairs instead of the elevator, etcetera.

Of course, Discourse II is not without contestants. Its main adversaries come from Discourse I. Both advocated approaches of obesity neatly fit into the 'agency' versus 'structure' mould that is typical for much of rightwing and leftwing politics respectively. This is not the case for Discourse III, in which the biological body is made the primary responsible agent.

Discourse III: The Body – Individualizing, but not Moralizing

The conditions in the womb might influence whether the foetus will in later life become obese or not. Getting either formula or breastfeeding the first 6 months of life is influential as well. Discourse III draws our attention to the possible biological causes of obesity, and especially to our genetic make-up.

If we look at genetic research in the preceding decades, we find that research has been largely directed at monogenetic diseases where one identifiable mutation

of a gene causes a certain disease. Healthy humans have a homeostatic system that regulates (using leptin and other hormones) the (energy)balance between input and output. The role of genetic factors has been researched by means of twin- and adoption research. Monozygotic twins that grow up in different environments tend to have the same body mass-index later on. Furthermore, their weight is comparable to their biological parents, not so much to their adoptive parents. (Parsons et al., 1999)

This third discourse combines elements of the two previous ones. In so far as it relates obesity to the genetic make-up of the individual, it is individualizing. Other agents are by and large deemed irrelevant within the parameters of Discourse III. However, the discourse does not moralize. It is not the individual's fault if (s)he suffers from weight problems. If we are unable to influence our body-weight by dieting and exercising, there cannot be a moral obligation to do so. In this way, geneticalisation helps to decrease the social stigma of obesity by removing its link with the weak will. Obesity is not a condition to be changed by the acts of a strong will. It is not a sin but an illness. This discourse can even result in a removal of moralisation per se, also for the actors highlighted in Discourse II. If people from different genetic groups react differently to junk food, how then can we hold McDonald's responsible?

Locating mutant genes causing obesity would open the door for the development of medical therapies that either compensate for the defunct genes or –in the future – even repair these. Responsibility for the solution of this spreading problem essentially rests with the medical scientists and professionals. The responsibilities of the individual and state are secondary: the first has to inform her/himself, the second has to stimulate scientific research and maybe facilitate the distribution of medication – when it will have been developed.

Discourse III is not without its contestants either. From the perspective of Discourse I the removal of moral guilt is to be deplored: slimming by following genetic technologies is seen as a technological fix. If we bet on genes, we lose our rationale to change the moral behaviour of the individual. From the perspective of Discourse II it will be pointed out that genetic factors cannot explain the recent rise in the obesity-statistics. And as in the first discourse, again the evaporation of blame and guilt will be deplored, be it that in this case it is the blame and guilt of actors like McDonalds. If we bet on genes, we risk losing our rationale to change society.

Conclusion: The Disruption of the Existing Discourses by Genomics

In this chapter we differentiated three discourses on obesity: Behaviour (individualizing and moralizing), Environment (collectivizing and politicising) and Body (individualizing and geneticalisation). Genomics doesn't fit in either of these discourses, and its emergence is bound to affect them in the coming years.

Genomics differs from genetics (as defined by us) in that it keeps its distance from genetic reductionism (be it mono- or polygenetic). Whereas genetics

concentrates on strictly genetic diseases, genomics typically deals with multifactorial afflictions. At the theoretical centre of genomics lies the axiom that by far the most genes do not come to expression in isolation from other genes and/or environmental factors. Genomics takes into account the complex interaction of genes and proteins, both in the cell and between cells, and their interactions with the environment. So, to take an example: in the case of developing an allergy for mustard, subjects both have to possess mutant genes *and* be exposed to mustard *and* this has to be done when they are in a certain age period.

This means that genomics combines elements of the three discourses described above. It admits of the importance of individual behaviour, of environmental factors, *and* of genes. A predisposition toward obesity may be 'written in the genes' but it is not inescapable. The inclination is for example age-dependent. A fat but otherwise healthy 2-years–old is no more likely than other babies to grow up fat. But as children age this 'window of plasticity' closes: an obese 15-year-old has about an 80% chance of being obese as an adult. (Shell, 2002, 185) Genomics deals not so much with diseases and certainties, as with risks, 'susceptibilities' and 'vulnerabilities' to become obese.

In a sophisticated statement Shell writes: 'The labyrinth of genes, peptides, and hormones regulating food intake is dense and Byzantine, extremely difficult to fool or manipulate. Knocking out one or a couple of components of this system with drugs is unlikely to work, because eventually other components step in to take their place' (Shell, 2002, 147). She expects that the number of the genes that play a potential role in obesity may be as high as sixty. 'What is certain is that an alphabet soup of molecules – neurotransmitters and neuroproteins – is involved in a network controlling the leptin response, and any slips along this pathway can, given certain environmental conditions, fool the brain into demanding more food than the body needs'. (Shell, 2002, 119). It is plausible that eventually genomics will give us some grips on the problem of obesity, but it is quite unlikely that a behavioural change, a change in the environment, or a new drug will ever do the trick alone. Combinations of these elements will in all probability be called for. In this way, genomics will invite the combination and fusion of the three discourses discussed above.

Maybe genomics can help us to integrate issues of food, agriculture, health and drugs in preventing and curing obesity in new ways. However, genomics also creates new problems and questions. Because of necessity of huge investments, private public cooperation ('triple helix', Etzkowitz and Leydesdorff, 2002; also Thackray, 1998) is more and more common. This creates new tensions. Regulations that were typical for the private sector, like patents, are now common in the public sector, like the universities. This development threatens to weaken the traditional academic ethic of independence and 'organized scepticism'. (van den Belt, 2003; Resnik, 1998) Similarly, genomics could create new divisions between rich and poor, or new inequalities between people with different genotypes (the so-called 'genomics divide'). These shifts create vast uncertainties, for which new ethical and political answers will have to be developed (Knoppers et al., 2000). Ethics and politics are not static entities in a technological culture. Scientific and technical developments continually reshuffle our ethical and political routines, concepts and strategies for

acting and perceiving (Pereboom, 2002). We would do well to think of both ethics and politics as dynamic searches for new concepts and vocabularies, rules and regulations, institutions and agreements to deal with emerging problems. Only in this way can we hope to guide the introduction of genomics into the domain of obesity.

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Chapter 4
Contesting the Obesity 'Epidemic': Elements of a Counter Discourse

Henk van den Belt

Introduction

In Chapter 3 of this volume, Tsjalling Swierstra distinguishes three discourses, all agreeing that obesity constitutes a pressing problem but each focusing on different causes of and solutions to this problem. Discourse I emphasizes the significance of personal behaviour, which is seen as under the individual's control; discourse II highlights the causal role of the environment, while discourse III puts the burden on the biological peculiarities of the human body. In this chapter I will discuss yet another discourse that stands orthogonal to the three discourses distinguished by Swierstra. As it challenges the dominant belief, shared by these three discourses, that the increasing prevalence of overweight and obesity constitutes a serious public health problem, it can appropriately be called a 'counter discourse'. Its adherents are to be found among a radical minority of overweight and obese people who refuse to follow the usual medical prescription to lose weight and instead seek recognition as being 'fat' people. These activists for 'fat acceptance' draw academic support from a handful of dissident researchers in universities and research institutes who criticize the three dominant discourses (especially discourse I). In fact, the 'fat acceptance' activists and the scientific dissidents who question the orthodox views on the deleterious consequences of excess body fat can be seen as together forming a *discourse coalition* (Hajer, 2003).

This chapter will explore and discuss in some detail the arguments that are put forward by the adherents of this discourse coalition. It is not my aim to pass a definitive judgment on the ultimate correctness of their arguments, but it must be admitted that the dissidents and sceptics often raise important points that perhaps need to be addressed more seriously by the supporters of the orthodox views.

A major component in the dissidents' campaign against the so-called 'anti-fat hysteria' is to draw attention to the enormous financial interests that are at stake for the diet and weight-loss industry in the accepted definition of obesity as a serious medical condition in need of urgent treatment. We cannot turn a blind eye to this

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mundane aspect, because it plays such a large role in the debate. After all, a CEO of Millennium Pharmaceuticals called obesity 'the trillion-dollar disease' (Shell, 2002, 2). However, we have to keep in mind that simply pointing out the interests that are advanced by a certain view is, logically speaking, never sufficient to discredit that view. In the concluding part of this chapter I will come back to the problematic nature of the attribution of allegedly distorting interests.

Disease, Risk Factor or What?

Entering the debate *in medias res*, let us focus on the contested status of obesity among a variety of advocacy groups and medical practitioners. Is it a disease, a risk factor, or what? Although the three dominant discourses agree that obesity constitutes a pressing problem, there is no consensus among the orthodoxy that it actually merits the disease label. Many would hesitate to call it a disease and be content with referring to it as a risk factor. Adherents of the counter discourse coalition, on the other hand, are united in their rejection of the disease label.

The view that obesity is indeed a disease is vigorously trumpeted by one prominent advocacy group, the American Obesity Association (AOA): 'We want obesity understood by the health care community and patients as a serious disease of epidemic proportions.' (American Obesity Association, n.d.). The AOA campaigns to disseminate this point of view and urges the Government to take measures that comply with this view, i.e. to make treatment costs tax-deductible and/or covered by insurance. The Association argues that obesity or the excess accumulation of body fat satisfies the common dictionary definition of disease as an 'interruption, cessation or disorder of a bodily function, organ or system'. According to Stedman's Medical Dictionary, moreover, a disease should have at least two of the following three features: recognised etiological agents; identifiable signs and symptoms; and consistent anatomical alterations. The AOA holds that obesity fully fits the bill:

> The 'recognized etiologic agents' for obesity include social, behavioural, cultural, physiological, metabolic and genetic factors. The 'identifiable signs and symptoms' of obesity include an excess accumulation of fat or adipose tissue, an increase in the size and number of fat cells, insulin resistance, increased glucose levels, increased blood pressure, elevated cholesterol and triglyceride levels, decreased levels of high-density lipo-protein and norepinephrine and alterations in the activity of the sympathetic and parasympathetic nervous system. One is also likely to find shortness of breath and back pain. The 'consistent anatomic alteration' of obesity is the increase in body mass. (American Obesity Association, n.d.).

On its website the American Obesity Association has enlisted several agencies and organisations, from the National Institutes of Health (NIH) and the World Health Organization (WHO) to the American Heart Association (AHA), which support the definition of obesity as a disease. However, the argumentation for the disease status of obesity that is offered here begs the fundamental questions at issue. Speaking of 'excess' accumulation of body fat implies a normative claim as to what amount of body fat is still considered to be within the range of 'normal'

variation and what amount has to count as 'abnormal', 'excessive' or 'pathological' (see Canguilhem, 1978, on the problematic distinction between the normal and the pathological). In general, a deviation at some distance from the mean of any trait may be an undesirable and unhealthy variation or just a statistical oddity. But no norm is explicated, let alone justified. The same holds for expressions like 'increased' blood pressure or 'elevated' cholesterol levels.

In an article entitled 'Is obesity a disease?', Stanley Heshka and David Allison critically remark that in recent years obesity is often labelled a disease by authoritative organisations like the NIH or the WHO, but that an explicit rationale for such labelling is seldom given. They concede that obesity may be associated with and contribute to increased risk for hypertension, coronary heart disease, type-two diabetes, dyslipidemia, cancer and cholelithiasis, but insist that 'being a risk factor for other diseases is not an accepted definition of disease.' (Heshka and Allison, 2001, 1401). The condition that a purported disease should exhibit a set of identifiable signs and symptoms is met in this particular case, 'but only in a circular or tautological sense: the only characteristic (pathonomic), identifiable sign of obesity is also the characteristic which defines obesity, i.e. fatness.' (Heshka and Allison, 2001, 1402).

Heshka and Allison hold that discrepancies in the usage of the disease label for obesity may reflect a process of social negotiation in which different organised lobbies and interest groups take part rather than a scientific dispute about evidence. Those who propound the disease label usually want to relieve obese persons from responsibility for their condition and to assign responsibilities to others for providing treatment and reimbursing costs (compare Chang and Christakis, 2002). Those who oppose the disease label, by contrast, may consider obesity a self-inflicted condition brought about by 'wilful' overeating or the result of behavioural choice, with no obligations placed on others to provide treatment or cover costs. As one proponent of the disease label argues, viewing obesity as a disease means that it 'is more likely to receive sympathetic attention by the public, the medical profession, and health care regulators' (Bray, 2004, 35).

Several divisions of the US government are also struggling with the question. While the Food and Drug Administration and the National Institutes of Health have considered obesity a disease for some time now, fiscal and health-insurance agencies are still hesitant to take responsibility for the substantial financial commitments resulting from this view (Borbély, 2001; Stein, 2003). For many years, the Internal Revenue Service (IRS) took the position that weight-loss programmes qualify for tax purposes as medical expenses only if they are undertaken at a doctor's direction to treat a specific disease, such as diabetes or a heart condition. Then in April 2002 it converted to the view that 'obesity is medically accepted to be a disease in its own right' and thus that expenses incurred for participating in weight-loss programmes for medically valid reasons (not just for improving your appearance!) under a physician's guidance would be tax-deductible (Associated Press, 2002). Other agencies like Medicare and health-insurance companies were also reconsidering their position (Medicare accepted the disease status of obesity in July 2004; see Stein and Conolly, 2004). Some warned that this change in policy might inaugurate a new

'spending binge' of billions of dollars on ineffective treatments ultimately to be paid for by the general tax-payer (Brennan, 2002).

There can be no doubt that the financial stakes in the debate about the disease status of obesity are considerable. As in other areas, corporations have found out that they can influence public opinion and promote their interests more effectively by working through seemingly independent organizations. Thus the American Obesity Association (AOA), formed in 1995, is nominally 'a lay advocacy group representing the interest of the 70–80 million obese American women and children and adults afflicted with the disease of obesity'. However, the Association 'receives most of its funding – several hundred thousand dollars in all – from the pharmaceutical industry, including Interneuron, American Home Products, Roche Laboratories, Knoll Pharmaceuticals Ltd., and Servier – all of which market or develop diet pills' (Center for Science in the Public Interest, 2003, 17).

Not all obese Americans, however, see the AOA as their legitimate mouthpiece or would subscribe to its policy of pushing for the disease label of obesity. There is a small but vociferous subgroup of obese persons who angrily reject the disease label without pleading guilty of the sins of gluttony, sloth or lack of will-power. They are organized in the National Association to Advance Fat Acceptance (NAAFA), based in Sacramento, California. Scorning the 'sympathetic attention' from others, they campaign for 'fat acceptance' and against 'size discrimination'. They may even count on a minority in the medical and scientific world as their allies (for a recent article jointly written by 5 dissident authors, see Campos et al., 2006). The NAAFA does not welcome the policy change of the fiscal authorities and health-care agencies. When obesity is seen as a disease, NAAFA opines, employers and others will be encouraged even more to discriminate against people whom they consider to be 'oversized'. NAAFA also strenuously opposes stomach surgery and the use of weight-loss drugs, which are usually ineffective and very often dangerous. Instead, the organization strives to promote the social acceptance and self-acceptance of people of 'all sizes of large'. In contrast to the AOA, NAAFA receives no corporate funding (see NAAFA website www.naafa.org).

NAAFA's rejection of the disease label of obesity can be contrasted with the more ambivalent viewpoint of the Dutch Obesity Association (Nederlandse Obesitas Vereniging), which endorses the status of obesity (and overweight) as a disease on rather pragmatic grounds: 'Within the Dutch Obesity Association we prefer to refer to overweight as a chronic condition, because somebody who has gained overweight will only very rarely lose it again. Treatments have very low percentages of success.' (Dutch Obesity Association website: www.dikke-mensen.nl). Here the disease status of obesity (overweight) is supported not to argue for the urgency of treatment but to caution against unrealistic expectations of treatment! The Association apparently does not want to make a strategic choice for 'fat acceptance' only: 'For the Dutch Obesity Association it does not matter [. . .] whether you have accepted your weight or whether you engage in a daily struggle with the scales. We are at your service' (Campos et al., 2006). Nonetheless, some board members of the Dutch Obesity Association share the main tenets of the counter discourse on obesity (see Jeurissen and van Spanje, 2001). The Dutch counterpart for the NAAFA is the 'Formidable

Movement' (Beweging van Formaat), which is a much smaller organisation (for the views of its founder, see Visser, 1995). It thus appears that a consistent campaign for fat acceptance cannot be pursued by organisations that strive to cater to the needs of the majority of obese and overweight people.

Numbers Games, Financial Stakes and Conflicts of Interest

For many militant members of NAAFA current initiatives to combat the so-called 'obesity epidemic' are little more than an 'anti-fat hysteria' in which overweight and obese persons are targeted as the primary victims. 'We are living in the middle of a witch hunt and fat people are the witches', NAAFA co-director Marilyn Wann declared at the 2004 annual meeting of her organization (Harris, 2004; Wann, 1999). In their eyes, official health agencies and the medical establishment have unleashed a war on the obese rather than on obesity. They resist the definition of the US federal government of obesity as a 'critical public health problem' costing more than $100 billion (based on Wolf and Colditz, 1998) and 300,000 lives per year.

The figure of a death toll of 300,000 lives per year in the USA due to obesity has been disputed by dissident researchers of the counter discourse coalition. The number originally derives from a study in the early nineties (Ginnis and Foege, 1993), and has been endlessly repeated in the media since it was first publicized in 1994 by former U.S. Surgeon General Everett Koop when he launched his Shape Up America! Campaign: 'A Lexis database search performed in September 2003 revealed mention of this statistic in nearly 2,400 news stories since 1998, and in more than 1,600 stories in the past two years alone' (Gaesser, 2003, 41). Yet the obesity dissidents asserted that there was no scientific evidence to substantiate this particular statistic.

A new and even higher estimation of a yearly death toll of 400,000 lives due to overweight and obesity was published in 2004 in a study co-authored by the chief of the Centers for Disease Control and Prevention, Julie Gerberding (Mokdad et al., 2004), only to be followed in April 2005 by another study conducted by CDC researchers which reduced the figure to 112.000 (Flegal et al., 2005). Needless to say, these disparities in numbers caused confusion: 'After trumpeting the highest estimate a year ago [in 2004] and warning that obesity deaths were poised to overtake those caused by tobacco, CDC officials now say that numbers are unimportant. The real message should be that "obesity can be deadly," says George Mensah, acting director of CDC's National Center for Chronic Disease Prevention and Health Promotion, "We really add to the confusion by sticking to one number."' (Couzin, 2005). But without trustworthy numbers to rely on, it is difficult to get the message of an alarming obesity 'epidemic' across.

Although several medical researchers would dispute the disease label for obesity while accepting its status as a risk factor, there are also a few investigators who would even deny that excessive weight as such constitutes a medical problem at all. Their views have been popularized by University of Colorado law professor Paul Campos in a number of iconoclastic articles and in his book The Obesity Myth. He

explains why it takes a lawyer rather than a doctor to represent the cause of obesity: 'Fat is on trial, but until now the defense has been mostly absent from the court of public opinion' (Campos, 2004, 4). Campos is the hero of the NAAFA militants and gave a talk at their 2004 annual meeting. (Strangely enough, he distanced himself somewhat from the organization and seemed to express some ill-concealed disgust at their all-too-fat members: 'The movement has found itself marginalized by drawing its membership and leadership from the far extreme of obesity. It will be more successful if it can attract the two-thirds of Americans who are being told by the government that they weigh too much – the I-want-to-lose-20-pounds crowd who are starting to feel a certain amount of resentment from the constant haranguing they're getting.' [Associated Press, 2004]). Campos sees the war on fat as a 'moral panic' about over-consumption in which persons of more than average size serve as scapegoats. Americans think being fat is disgusting, but hanker for a quasi-medical rationalization to make their psychological revulsion respectable.

Campos also points out that the 'anti-fat hysteria' is immensely profitable for large segments of the medical and pharmaceutical industry. Indeed, this industry actually has a vested interest in the continuation of the prevalent belief that overweight and obesity constitute a serious health risk. In a sharply cynical passage he writes:

> Consider this: from the perspective of a profit-maximising medical and pharmaceutical industry, the ideal disease would be one that never killed those who suffered from it, that could not be treated effectively, and that doctors and their patients would nevertheless insist on treating anyway. Luckily for it, the American health care industry has discovered (or rather invented) just such a disease. It is called 'obesity'. Basically, obesity research in America is funded by the diet and drug industry – that is, the economic actors who have the most to gain from the conclusion that being fat is a disease that requires aggressive treatment. Many researchers have direct financial relationships with the companies whose products they are evaluating. (Campos, 2004, 41)

Close financial affiliations between scientific experts and the weight-loss industry with all the dangers they entail for ensuing conflicts of interest and research biases have also been noted and documented by others:

> Diet and pharmaceutical companies influence every step along the way of the scientific process. They pay for the ads that keep obesity journals publishing. They underwrite medical conferences, flying physicians around the country expense-free and paying them large lecture fees to attend (Fraser, 1998, 299).

Paul Ernsberger and Richard Koletsky point out that seven of the nine members of National Task Force for the Prevention and Treatment of Obesity, an official expert panel instituted by the NIH, were directors of weight-loss clinics. It can hardly be a coincidence, they claim, that the reports issued by the Task Force have generally been favourable to weight-loss clinics and to pharmaceutical firms marketing diet pills (Ernsberger and Koletsky, 1999, 251). Thus in 1994 the NIH National Task Force issued a report on weight cycling, or 'yo-yo dieting' in popular parlance (NIH, 1994). According to Ernsberger and Koletsky, there is overwhelming evidence that repeated loss and regain of weight increases deaths from cardiovascular disease and has other adverse effects (see also Gaesser, 2003, 42). Yet the NIH

panel declared that weight cycling is not harmful and that its perceived risks should not deter anyone to enter a weight-loss programme, a conclusion that was widely echoed in the mass media. This conclusion is obviously in line with the interests of the diet industry: 'Recognition of the hazards of repeated loss and regain of weight is a serious threat to the weight loss industry [. . .], as they depend on repeat business for their survival. Given the high prevalence of dieting, if only persons who had never dieted before were encouraged to join weight loss programs, the industry would collapse overnight.' (Ernsberger and Koletsky, 1999, 251).

In another report, issued in 1996, the Task Force endorsed the use of diet drugs such as fenfluramine and phentermine (sometimes used in combination in the cocktail 'fen-phen') for long-term periods, downplaying their negative side-effects and arguing that such risks as are there must be seen 'in the context of the major excess in morbidity and mortality attributable to obesity' (NIH, 1996). In April 1996 *dexfenfluramine* (the right-handed isomer of *fenfluramine*, also known as Redux) gained FDA approval for long-term use. Sales of this drug, but also of the sister drugs *fenfluramin*e (Pondimin) and *fen-phen*, received an enormous boost in the subsequent months. The distributor, Wyeth-Ayerst (a subsidiary of American Home Products), 'ghostwrited' scientific articles for Excerpta Medica to enhance consumer awareness of the health risks associated with obesity (one of the 'authors' of 'ghost-written' articles was F. Xavier Pi-Sunyer, an academically respected obesity specialist who also served on the Task Force; see Shell, 2002, 138; for an insider account on 'ghost-writing' in pharmacology see also Healy, 2004).

While the FDA decided to admit Redux to the US market, an international team assembled in France was about to conclude its 3-year investigation into the risks of developing primary pulmonary hypertension (PPH) for patients taking the drug. It estimated a frequency of 23–46 cases per million patients per year. The results of the study were to be published in the prestigious *New England Journal of Medicine* of August 29, 1996 (Abenheim et al., 1996). One week before publication cardiologist Stuart Rich, the American member on the international research team, warned that the risks might be even higher because numbers seemed to spiral up after usage of the drug for more than 1 year (earlier studies had looked at patients who used the drug only for 3 months). What worried Rich especially was that Redux was massively and indiscriminately used not only by obese persons but also by people who were just a few pounds overweight (CNN.com, 1996). Rich hoped that American doctors would stop prescribing the drug so often after the medical journal came out (Liebman, 2003). However, the editors of the *New England Journal of Medicine* had asked two experts in the field of obesity research, JoAnn Manson and Gerald Faich, to write an editorial for the same issue in which they had to put the study results into perspective for the readers of the journal. Their solicited editorial put a special 'spin' to the outcomes of the international study (Manson and Faich, 1996a).

JoAnn Manson has been called 'the leader of the alarmist school of obesity research' Klein and Fumento, n.d.. In the well-known Nurses' Health Study published in September 1995, she and her co-authors claimed to have established increased mortality risks for overweight and obese women (Manson et al., 1995).

In the cohort of more than 115.000 women followed for 16 years in this study, the risk of death was 60–70% higher among those who had BMI's between 29 and 32 than among those with BMI's between 25 and 27. These findings entail that in a single year 1260 excess lives would be lost per million women as a consequence of an average weight difference of only 13 kg. Although the Nurses' Health Study has been criticised on methodological grounds, it was against the background of these findings that Manson and Faich judged the risks of using Redux and other appetite-suppressant drugs in their solicited editorial: 'It is in the context of [the] benefits of weight reduction that the risk of primary pulmonary hypertension must be interpreted' (Manson and Faich, 1996a, 659). The two editorialists also suggested that several biases might have inflated the risk estimate of PPH in the international study. They calculated a benefit:risk ratio of 20:1 for the use of Redux ('280 lives saved as compared with 14 deaths caused by the drugs per million person-years of treatment'). Thus the final sentence of their editorial urged doctors and patients not to be unduly worried about the possible side effects of Redux: 'Although physicians and patients need to be informed, the possible risk of pulmonary hypertension associated with dexfenfluramine is small and appears to be outweighed by benefits when the drug is used appropriately' (Manson and Faich, 1996a, 660).

Only belatedly did the editors of the *Journal*, Marcia Angell and Jerome Kassirer, become aware that their guest editorialists had both been paid consultants for companies that stood to gain from the sale of dexfenfluramine (Redux) (Angell and Kassirer, 1996). In November 1995, during the FDA review process, Manson had served as a scientific consultant on the health risks of obesity on behalf of Interneuron Pharmaceutical (the US sponsor of dexfenfluramine) and Servier (the European manufacturer). Similarly, her co-editorialist Faich had served as a consultant to Servier and Wyeth-Ayerst (the North American distributor of dexfenfluramine) and was still serving as a consultant to the latter company at the moment of publication. This was in clear violation of the policy of the *Journal* to bar editorialists and authors of review articles having any financial connection with a company that benefits from a drug or device discussed in the editorial or review article. In a reply to the *Journal*'s attempt to set the record straight, the guest editorialists responded that their failure to disclose any conflicting interests was based on a series of misunderstandings (Manson and Faich, 1996b). However, *Journal* editors Angell and Kassirer took the matter extremely seriously. In their view, given that the editorial had been written by paid consultants to companies that sell dexfenfluramine, the editorial's conclusion that the benefits of Redux outweighed its risks raised 'troubling questions': 'Did the authors give sufficient attention to the possibility that the risks associated with long-term use would be even greater? Were they too quick to attribute the risks associated with obesity to obesity itself? [*This seems to be an implicit criticism of the methodology used in the Nurses' Health Study! – HvdB*] Were they too dismissive of other, nonpharmacologic treatments of obesity?' (Angell and Kassirer, 1996, 1055). According to Angell and Kassirer, a mere disclosure of conflicts of interest would not have helped readers to make up their minds for themselves, hence the strict policy of the *Journal* to bar editorialists with any financial ties to companies that stand to gain from their comments. Manson and Faich, however, saw the issue in a different light: 'The views expressed in the editorial are entirely independent and have not been influenced by industry.

Moreover, we believe that collaborations between science and industry are essential to the advancement of public welfare and the development of increasingly safe and effective therapies' (Manson and Faich, 1996b, 1065). In another journal, however, Manson complained that she and Faich had actually been pilloried by the editors of the *New England Journal of Medicine* and by the media (Manson, 1997; for pertinent comments on the affair, see also Horton, 1997).

Despite the ensuing scandal about conflicts of interest, the guest editorial that accompanied the international study on the risks of appetite-depressants may have persuaded many doctors to continue prescribing Redux and its sister drugs (Liebman, 2003). The real scandal became fully manifest only in October 1997, when the FDA had *fenfluramine* and *dexfenfluramine* withdrawn from the market. It turned out that some 30% of users had suffered primary pulmonary hypertension, heart-valve damage or other serious injuries. In the wake of a series of product liability cases, American Home Products announced in 2001 to set aside the staggering amount of $12 billion to cover future settlements in litigation (Shell, 2002, 141). How could such a scandal have come about and how could such an unsafe product as *dexfenfluramine* have gained FDA approval in the first place? It may have something to do with the prevalent attitude towards obesity that is aptly summarised by an FDA officer: '[The drug companies] and the people they've paid off in academic medicine [have portrayed] obesity as a lethal threat, like anthrax. Anything that "works" should get on the market, because the alternative is that thousands will die of the side effects of obesity. But none of these drugs improve health over the long term. And the risks of these drugs are very real.' (Bruce Schneider, quoted in Shell, 2002, 147). In the prevalent risk equation, the hazards of drug use and weight-loss treatment are too easily discounted against the presumed high risks of obesity.

Weighing Up Obesity Research

Given the prevalence of potential conflicts of interest in the field of obesity research, who are we as simple laypersons to rely on? Can we believe what we read? Can we trust authoritative statements made by official institutes? The dissidents tend to foster our doubts. Ernsberger and Koletsky provide an extensive scrutiny of the existing medical literature on the health effects of obesity. They observe a very pronounced pattern of selective citation. Articles that assign a high risk to obesity, regardless of journal stature or data quality, are much more often cited than neutral and sceptical articles. It also happens that an NIH panel formulates a so-called 'consensus statement' ostensibly based on expert testimony, but that is actually completely at odds with the conclusions of the experts who testified to the panel. In one case, for example, the expert testified that obesity is not related to atherosclerosis, but the panel conclusion stated nonetheless that obesity causes atherosclerosis (Ernsberger and Koletsky, 1999, 250).

There are a lot of epidemiological studies on the relationship between body weight and morbidity and mortality. Such studies need careful analysis and interpretation before proper conclusions can be drawn with any degree of confidence. After all, mere correlation does not establish causality. Even on the basis of a relatively straightforward analysis of the available epidemiological data, however, it

can already be argued that the current setting of body weight standards shows a clear bias in favour of the weight-loss industry. Conventional wisdom has it that the ideal body weight corresponds to a BMI in the range of 19–22; persons with a BMI of more than 25 are officially considered 'overweight', while having a BMI above 30 makes you an 'obese' person. Most epidemiological studies have shown a U-shaped relationship between BMI and mortality. This U-shaped relationship also emerges in a quantitative meta-analysis of 23 major studies performed in 1996 by researchers at the National Center for Health Statistics and Cornell University (Troiano et al., 1996). The resulting curve shows the lowest mortality in the BMI range between 23 and 29. This would mean that a majority of the healthiest men and women covered by these surveys would be considered 'overweight' by official standards. Concern with health hazards is also one-sided in that the current obsession is only with the right-hand end of the U-curve, while virtually ignoring its left-hand end, or in other words the health hazards of being 'underweight'. However, setting body weight standards as low as possible obviously serves the interest of the diet industry by expanding its client base (Ernsberger and Koletsky, 1999, 249).

Many epidemiological studies show that obese persons, especially those with BMI figures exceeding 35, suffer indeed from worse health than leaner persons. Ernsberger and Koletsky do not deny this relationship, but are reluctant to attribute causality to obesity as such. This caution is warranted because most studies done by obesity experts are cross-sectional surveys that do not admit drawing causal conclusions. Controlled clinical trials, the gold standard in medical research, are the only type of research design that warrants direct causal inferences. A controlled clinical trial would require a group of obese persons to be divided into two groups: one to be cured of their obesity by some form of treatment, and a comparison group that would not be treated. Ironically, this ideal research design is not possible because there are no effective treatments for obesity! The methodological fallacy committed in most studies attributing the ill health effects to a heavy body mass is the failure to consider, and control for, possible confounding factors. Ernsberger and Koletsky hold that the seemingly negative consequences of obesity can actually be blamed on such factors as weight cycling (or alternate starving and bingeing), the use of diet pills, poor diet, sedentary lifestyle, lower socio-economic status, lack of access to medical services owing to social stigma en low self-esteem, and social discrimination by health professionals. If you control for these factors, the apparent relationship between high body weight and ill health virtually disappears.

One immediate consequence for the medical practitioner is that the one-sided focus on the goal of losing body weight should be dropped. The aim is not to treat obesity, but to treat the afflictions from which obese persons (and others) may suffer. Thus doctors should deal directly with such conditions as hypertension, type-2 diabetes, hyperlipidemia, and sleep apnoea (for which effective treatments are indeed available), instead of prescribing weight loss as the primary treatment, which is elusive and dangerous and merely delays the initiation of effective therapy. Ernsberger and Koletsky are however well aware that the change in focus they propose may amount to nothing less than a veritable paradigm shift in medical thinking about obesity:

The position of weight loss in medicine today can be compared to the role of bloodletting 150 years ago. Bloodletting became popular because doctors found that if feverish patients were bled, their fever would break and their skin would become cool and clammy. Thus bloodletting improved the symptoms of sick patients. Of course, we now know that blood loss creates a state of shock that lowers body temperature but ultimately increases the risk of death. Similarly, weight loss produces short-term improvements in symptoms but may not be ultimately beneficial. Before weight loss can be removed from its exalted status as a therapy, a revolution in medicine may be required comparable to the one that brought an end to the practice of bloodletting. (Ernsberger and Koletsky, 1999, 233–234).

'Fat But Fit'

Since Ernsberger and Koletsky gave a critical scrutiny of the existing literature on the morbidity and mortality risks of overweight and obesity, several new epidemiological and statistical studies have been published which again seem to confirm the health hazards of being seriously or even moderately oversized (Allison et al., 1999; Fontaine et al., 2003; Calle et al., 2003). Once again, the conclusions drawn from such studies (and/or their presentation in the mass media) have been called into question. Sometimes there is a notable disjunction between the actual data of these studies and the alarmist headlines in the media to which they typically give rise. One example is the study by Calle et al., which showed a mortality rate from cancer of 5.78 deaths per one thousand in the 'ideal weight' category (BMI between 18.5 and 24.9) as compared to a rate of 5.46 deaths per one thousand in the 'overweight' category (BMI between 25.0 and 29.9) (Calle et al., 2003, 1628, Table 4.1). So the death rate among the officially 'overweight' category in this study was actually slightly *lower* than the death rate among the officially 'ideal weight' category! Yet the authors drew the misleading conclusion that '90,000 deaths due to cancer could be prevented each year in the United States if men and women could maintain normal weight [i.e. keep their BMI below 25.0 – HvdB]'(Calle et al., 2003, 1637). It was this conclusion that was eagerly taken up by the mass media, thus adding fuel to the 'anti-fat hysteria'. Sometimes the quantitative results are overly dramatised

Table 4.1 Some book titles of the popular counter discourse

Jarrell, Donna, 2000, Fat Chicks Rule!: How To Survive in a Thin-Centric World
Jarrell, Donna, 2005, Scoot Over, Skinny: The Fat Nonfiction Anthology. Gamble Guides, Harvest
Erdman, Cheri K. Nothing to Lose: A Guide to Sane Living in a Larger Body
Manheim, Camryn, 2000, Wake Up, I'm Fat! Broadway
Lynn, B., The Big Girls' Guide to Life: A Plus-Sized Jaunt Through a Body-Obsessed World
Palmer, Liza, Conversations with the Fat Girl
Shanker, Wendy, The Fat Girl's Guide to Life
Wann, M., 1999, FAT! SO?: Because You Don't Have to Apologize for Your Size, Ten Speed Press

by presenting them in percentage terms while neglecting the low absolute levels of risk. One study, for example, found a death rate from cardiovascular disease among non-smoking 'mildly obese' women that was 60% higher than the death rate among non-smoking thin women. Yet,as Paul Campos points out, '60% more than almost nothing is still almost nothing' (Campos, 2004, 16).

Often the debate is about how to adjust for and control possible confounding factors. Unfortunately, the numerical data do not speak for themselves but have to be subjected to all kinds of statistical manipulation before they will reveal their 'true' meaning (for other examples of disputed outcomes of epidemiological research, see Tannahill, 1992). The dissidents criticise many studies for having failed to control for particular confounding factors that they consider relevant (e.g. weight cycling, use of diet pills, low socio-economic status, limited access to health care, etc.) (Gaesser, 2003, especially 41–42). Sometimes there is also disagreement about whether particular controls are appropriate or not. JoAnn Manson and her collaborators, for instance, always insist on controlling for smoking status: 'Another confounder of the association between weight and mortality is smoking status. Because smoking is more prevalent among lean individuals and is also a strong independent risk factor for death, failure to adjust for its effects will produce an artifactually elevated mortality among the lean.' (Manson and Bassuk, 2003, 230). Paul Campos, however, believes that this procedure is inappropriate because the relationship between thinness and smoking is far from being a coincidence: smoking is a common weight loss and weight maintenance strategy. One could just as well conclude that 'being or remaining thin [is] the most significant risk factor for the behaviour – smoking – that itself [is] by far the deadliest risk factor.' (Campos, 2004, 14). Removing smoking from the equation, Campos holds, is tantamount to removing anorexia and bulimia from a study that is supposed to measure the relative health risks of fatness and thinness. Whether this comparison is appropriate is a matter of judgement (compare Austin, 1999, 258).Unravelling causality in epidemiological studies remains highly problematic and highly controversial.

A group of authors led by Katherine Flegal from the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, has pinpointed still other methodological pitfalls in the various attempts to estimate the number of deaths attributable to obesity in the United States (Flegal et al., 2004). Such studies routinely correct for baseline health status by excluding persons with heart disease or cancer or other conditions, yet these very controls make the outcomes less representative for the *entire* national population: 'Persons excluded from epidemiological studies are often those at higher risk of death and may also be those most likely to die of factors unrelated to obesity' (Flegal et al., 2004, 1487). The results obtained by such studies apply only to a subgroup of the population and cannot readily be extrapolated to deaths in the entire population. Flegal et al. also warn that overall estimations are also extremely sensitive to small variations in relative risks among the elderly (because that is the group in which most deaths occur). Current estimates of the number of deaths attributable to obesity should therefore be handled with extreme caution.

Laypersons who want to assess the empirical evidence on the health risks of overweight and obesity in order to make an independent judgement on their own

accord, may thus easily become stuck in the nitty-gritty of methodological arguments about the possible confounding factors that should or should not be controlled or adjusted for. Alas, there is no easy remedy for this problem, as there is no shortcut – no 'royal road' – to true scientific insight. One possible confounding factor, however, deserves to be highlighted, for it directly relates to the practical concerns of laypersons beyond the confines of academic debate. This is the factor of 'fitness' or 'physical exercise'.

The failure to adjust for physical activity in most epidemiological obesity studies is not a minor omission. Surely, overweight and obese persons are more likely to be sedentary and have lower fitness levels than their leaner counterparts. However, researchers at the Cooper Institute for Aerobics Research in Dallas, Texas, have tried to disentangle the effects of the two factors, weight and fitness. They measured cardio-respiratory fitness (CRF) using maximal exercise treadmill tests. One major finding was that fitness has a beneficial effect on morbidity and mortality rates *quite independently of body weight*: 'Obese individuals with at least moderate CRF have lower rates of cardiovascular disease (CVD) or all-cause mortality than their normal-weight but unfit peers.' (Blair and Church, 2004, 1232). Already fairly modest levels of physical activity would do the trick, such as the officially recommended 30 min a day of brisk walking, bicycling or swimming (or equivalent amounts of energy spent in housework or gardening). To dissidents like Glenn Gaesser, professor of exercise physiology at the University of Virginia, findings such as these provide strong grounds to adopt a new approach to health and fitness, one that places less emphasis on body weight or body fat and more emphasis on a healthy lifestyle. He thus coined the slogan 'health at every size' (Gaesser, 2003, 44). Naturally, members of the National Association to Advance Fat Acceptance (NAAFA) eagerly embraced the happy message that you can be 'fat but fit'.

As was to be expected, however, the alarmist school of obesity research refused to swallow the new message. 'A person who is both fit and fat is a rare bird', JoAnn Manson declared rather bluntly (quoted in Stenson, 2003). Michael Fumento, a lawyer and popular writer who specializes in fierce polemics against fat acceptance groups, went one step further: '[C]onsidering that lack of exercise is one of the two reasons people become fat (the other being excess eating), "fat but fit" is practically the equivalent to "blonde but brunette".' (Fumento, 2002). That would make it *a priori* inappropriate to try to separate and disentangle the effects of body weight and fitness level, just as Campos saw no point in separating the effects of thinness and smoking. However, despite (or perhaps because of) the presumed rare occurrence of birds that are both fit and fat, Manson was not willing to yield an inch on the old policy line: 'It is inappropriate to give the public-health message that obesity doesn't matter as long as you exercise' (Stenson, 2003).

For their part, Steven Blair and Tim Church of the Cooper Institute in Dallas cautiously attempted to stake out a common ground between the contending factions:

> In essence, physical activity is the common denominator for the clinical treatment of low fitness and excess weight, making the 'fitness vs. fatness' debate largely academic. Thus, physicians, researchers, and policymakers should spend less energy debating the relative

> importance of fitness and obesity and more time focusing on how to get sedentary individuals to become active. With 40–50 million adults in the United States currently not obtaining the recommended amount of daily physical activity, motivating the individuals to incorporate physical activity into their daily lives, whether to lose weight or reduce risk of chronic disease, will have substantial health and financial benefits at an individual and societal level. (Blair and Church, 2004, 1233).

Conclusion

Dissidents who question the prevalent definition of obesity as a disease or a serious medical problem in its own right – medical researchers like Paul Ernsberger, Richard Koletsky, and Glenn Gaesser, and popularizing authors like Paul Campos and Laura Fraser – usually point at the huge financial interest that the diet-pharmaceutical complex has in this very definition. However, pointing out the underlying economic interest a particular actor has in a certain view may be an effective tool of 'debunking', but does not by itself establish the falsity of that view. Arguing that it is in the obvious interest of the weight-loss industry to conclude that 'weight cycling' is harmless, for example, does not prove the invalidity of that position. To establish the latter would require additional argumentation on the basis of empirical evidence (which Ernsberger, Koletsky and Gaesser duly attempt to provide). Still, the fact that so many researchers are, in one form or another, financially rewarded by the companies that stand to gain by their research findings is cause for legitimate concern and suspicion. After all, the proverb says 'He who pays the piper calls the tune'.

The trouble with the 'interest argument' is that it can work several ways. One might claim, for example, that the researchers affiliated with the Cooper Institute (like Steven Blair and Tim Church) or with sports medicine (like Glenn Gaesser) also have a definite stake in the outcomes of their research. It is presumably in their interest that people who follow exercise programs do not drop out if the hoped-for weight loss fails to occur. Hence the argument that physical activity is good in itself, regardless of its possible effects on weight:

> Exercise and healthy eating should not be viewed merely as a means to an end (weight loss), but rather as having their own intrinsic value (psychological and physical). If someone quits an exercise program out of failure to reach a particular weight loss (or reduced body fat) goal, then all the benefits of the exercise are lost as well. Far too many people who start exercise programs do not stay with them. Indeed, 'yo-yo fitness' is becoming as common as yo-yo dieting. (Gaesser, 2003, 45).

Moreover, it is not necessarily *financial* conflicts of interests that cause most concern, as Richard Horton, editor of *The Lancet*, rightly emphasises (Horton, 1997). Other commitments may also generate bias; they could be even more problematic if they go unrecognised. Thus Michael Fumento has suggested that 'fat acceptance' may become the new political correctness. He accuses the obesity dissidents of telling fat people what they *want* to hear rather than what they *need* to hear (Fumento, 2000). According to Abigail Saguy and Kevin Riley, in the debate on the health effects of overweight and obesity fatness itself is seen as a conflict of

interest: 'the fact that most fat acceptance activists are very fat women discredits them as simply making excuses for their weight' (Saguy and Riley, 2005, 906). It is only due to the fortunate circumstance that Glenn Gaesser happens to be thin and Paul Campos is currently in 'good shape' that their sceptical messages on the health effects of overweight and obesity could not be so easily dismissed by using the *ad hominem* trump.

It is not just the diet and pharmaceutical industries and the fitness branch that have stakes in the outcomes of obesity research. What about the (fast) food and restaurant industries that increasingly feel the brunt of public outrage over the 'obesity epidemic'? In fact, their front organisation, the Center for Consumer Freedom, recently brought out a brochure entitled *An Epidemic of Obesity Myths*, in which all the arguments of the obesity dissidents are eagerly embraced (Center for Consumer Freedom, 2004). The Center describes itself as 'a 501(c)(3) nonprofit organization supported by restaurants, food companies, and individual consumers together to promote personal responsibility and protect consumer choices', but Michael Fumento gives a description that is somewhat less flattering: 'The CCF is funded by restaurants and food and beverage companies whose advertising and T-Rex-sized food and drink portions encourage us to cram our craws with the most caloric stuff on earth' (Fumento, 2004; for information about membership of the 1998 advisory panel of the CCF and about contributions in 2001 and 2002 and before, see Center for Science in the Public Interest, 2003, 22 and *September 2003 Update*, 1–2). If the dissidents' arguments are used to serve the purpose of deflecting public criticism of the U.S. food and restaurant industry, does that make them scientifically suspect?

Of course, the problem is not confined to the area of obesity research and the weight-loss and food industries. There is an extensive body of journalistic and scholarly literature indicating that the credibility of scientific findings may become problematic when the research has been funded by commercial sponsors (Angell and Relman, 2002; Krimsky, 1999; 2003; Horton, 2004; Lexchin et al., 2003). The key-expression here is *conflicts of interest* (van Kolfschooten, 2002; Krimsky, 2005). In a somewhat provocative paper, sociologist Arthur Stinchcombe argues that the 'communism of knowledge' in the sense of Robert Merton's scientific ethos forms the hard core of the global capitalistic information economy: 'Only socialism, either in the form of government control of certification of quality in the FDA, or in the communism of knowledge in the university, can produce the fantastic advertising value of a clinical trial with a control group. The reason the United States can dominate the world drug market is because it has a socialist advertising agency [. . .].' (Stinchcombe, 2001, 13). Yet, if we are to believe Marcia Angell and Arnold Relman, even this allegedly 'socialist' advertising agency is on its way to become the captured institution of the pharmaceutical industry: 'Over the past decade, the FDA has become increasingly friendly with the industry it regulates. Indeed, it sometimes seems as if the FDA views drug companies, and not the American public, as its primary client' (Angell and Relman, 2002, 108). A case in point is FDA's handling of the review process on dexfenfluramine. Another field where conflicts of interest have run rampant is biotechnology. Who is the public to believe in the

controversy over the environmental risks of GM crops, when the scientific protagonists and antagonists are either aligned with the biotech industry or with anti-biotech NGOs (Scott, 2003)?

Recent developments in the field of psychopharmacology research also give food for thought. Psychiatrist David Healy notes how the nervous problems of patients and clients have been successively described in terms of tension and stress before the mid-1980s, in terms of panic attacks in the late 1980s, and in terms of moods in the 1990s, depending upon the marketing strategies pharmaceutical companies deployed for selling successive generations of drugs. Pharmaceutical research is thoroughly commercialised (with widespread use of 'ghost-written' articles where academic celebrities lend their name to the promotion of a particular product) and an integral part of the marketing effort aimed at shaping consumer consciousness of the underlying 'problem' the available drugs on offer are supposed to address ('awareness' campaigns). Paraphrasing Marx, Healy states: 'It would seem that he who controls the means of data production controls consciousness' (Healy, 2004, 234). In a similar vein, Sergio Sismondo argues that '[. . .] recent and current marketing campaigns for pharmaceuticals are putting in place a new understanding of the nature of illness and health. Whereas bodies once were understood as normatively healthy and only sometimes ill, they are now understood as inherently ill, and only able to be brought towards health. The treatment of risk factors, for illness, and not just illness, is a development linked to prospects of dramatically increased sales of drugs [. . .].' (Sismondo, 2004, 157–158). As Healy explains, 'If 1 per 100 has a disease but 10 per 100 carry a risk factor, conventional medical models will mandate the treatment of the one diseased individual, whereas the new emphasis on risk mandates the treatment of 10. Risk thresholds furthermore can be ratcheted down progressively, creating ever-larger markets' (Healy, 2004, 237).

Is it just the effect of a too lively imagination to discern an uncanny resemblance with the dominant discourse on obesity here?

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Chapter 5
Three Main Areas of Concern, Four Trends in Genomics and Existing Deficiencies in Academic Ethics

Michiel Korthals

Introduction

Now that we have delineated the three discourses and one counter-discourse about obesity, and have paid some attention to genomics, in this chapter (after providing more details about obesity) we address the following questions: 'Which ethical issues are prominent in this interaction between genomics and obesity?' and 'Which ethical vocabularies for thinking, speaking and acting about technological developments in interaction with societal problems are available and fruitful?' The emergence of genomics technologies in the areas of food and healthcare in battling obesity will lead to new responsibilities and to shifts in the current allocation of responsibilities. We end this chapter with a discussion of some pragmatist suggestions to improve the situation. We elaborate more thoroughly upon this aspect in later chapters.

Obesity, the Phenomenon

Obesity is often defined as an imbalance between the input and output of energy, but this simple definition covers many complex aspects. The input (such as the intake of food and drugs) can cause overweight (Shell, 2002), although one has to make a qualifier here, because it could also be the case that the bodily processing of the input is distorted (Taubes, 2008). Information about intake can be acquired by asking consumers, but these self-reports are usually not seen as being very reliable. Biomarkers (Hill, 2002) are considered to be more informative, but it is still unclear which ones are really necessary. Next, the storage and processing of food ingredients in the body has its own complexities. Here we have two trajectories connected to the human metabolism that run from fat making ingredients in the food to fat production in the body (Hill, 2002). Moreover, there is appetite, which is the subject of behavioural genomics and especially involves satiety (appetite control). Lastly

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there is the output of energy, by movement of the body, which, however, can also influence the input and throughput.

Obesity is seen by many as an epidemic and is attracting growing interest from governments, industry and public health organizations. According to recent studies, 50 million Americans have severe overweight. The OECD study on health in OECD lands indicates that obesity is also a serious problem in other countries. In the UK, 20% of the population is overweight, in Germany this figure 11.9%. Moreover, obesity is connected with the Western lifestyle (directly related to for instance watching television), so even in many developing countries obesity is a greater problem than undernourishment (Lang, 2002).

Obesity in adulthood can have the same shortening effect on life expectancy as smoking (Peeters, 2003). It results in a greater vulnerability for cardio-vascular diseases, diabetes II and several types of cancer. Although there are some who try to defend obesity as a form of social appreciation or disappreciation, epidemiological and biological studies make it clear that there can be no doubt that obese people have much higher risk for disease. Indeed, there can be many reasons for people being severely overweight, and eating disorders are one cause. However, but obesity is not merely overweight, but also has many individual and social immaterial and material costs (Fontaine et al., 2003).

The fate of obese children is exemplary for the problems of unclear responsibility and the social dilemmas of individual freedom of choice that the obese are facing. Obese children cannot give their consent and they lack the cognitive abilities to become well informed about food and lifestyle. However, their vulnerability is not only due to their lack of cognitive and moral competence to manage their own lives, but also to their familial context, which can be an obstacle to healthy living, both socially and genetically. Several studies indicate that parental obesity more than doubles the risk of adult obesity among both obese and non-obese children under 10 years of age. One author states:

> [...] parental obesity significantly alters the risk of obesity in adulthood for both obese and non-obese children, especially those less than 10 years of age. Obesity in one or both parents probably influences the risk of obesity in their offspring because of shared genes or environmental factors within families (Burniat, 2002; Whitaker, 1997).

Children not only inherit the genetic profile of their parents, but also the obesity-related behaviour of their parents or friends. Even in the case where parents do not have obesogenic behaviour, children live in an obesogenic environment that makes it very difficult for parents to withstand the constant pressure of industries that earn their money from selling products that lead to obesity.

It is very plausible to assume that genomics can assist in diagnosing, preventing and curing obesity by researching the role of genes, proteins, enzymes and hormones and their interactions. Genomics comprises the sciences and technologies along the pathways beginning with DNA until the organism is finally built and sustained: the range of genes (DNA), transcriptor factors, enhancers, promoter, RNA (copy of DNA), protein, proteins, cell metabolism, cellular interactions and the organism itself. Generally speaking, each x-omics discipline tries to build a strong position

around its distinctive node on the molecular pathways (genome, transcriptome, proteome, metabolome, etc.). Every node is assigned teams and programmes, and that is how nature (i.e. the DNA information they are working on) is socialized.

At several locations along these pathways, obesity and obesity-related issues are addressed. Obesity means that there is an imbalance in the input and output of energy, so wherever genes, proteins, enzymes and hormones play a role in the input (intake of food, drugs), storage, and output (exercise), genomics can assist in diagnosing, preventing and curing obesity. However, these new disciplines are not the first or the only ones to study obesity.

Three Main Areas of Ethical Concern

Everyone wants to be healthy, but many of us disagree about what role health should play in life, what the meaning of health is, and we also refuse to act in healthy ways (at least according to the dominant view). This general remark also applies to obese individuals. As we have seen from Chapter 4 on the counter-discourse, many obese and non-obese persons doubt the health definitions that are established by governmental and professional circles. In general there can be a reasonable controversy on questions such as: 'What bearing, if any, should our food, health and life choices have on the ethics and policy of food production, food policy, clinical practice and health policy? Should risk-takers have the same claim on scarce resources, such as organs for transplant, as those whose plight is due to no choices of their own? And is there any reason not to impose fees and taxes on risk-takers, be they smokers or mountain climbers, to defray the added expense of the care they may need? In health resource allocation aimed at reducing the burden of disease, should we regard certain burdens as individual responsibilities: for example, dealing with stigma, or caretaking for family members?'

These questions can be organized according to the three main areas of ethical issues connected with genomics that are aimed at tackling the problem of obesity. Due to the fact that genomics, when applied to obesity, unmistakably addresses either food or the digestion of food in humans, we will not pay heed to other aspects that connect with obesity, such as physical exercise. The first area concerns the relationship between *health and food*. The second ethical area concerns the relationship between *social or public health and nutrition, and personalized or individualized health and nutrition*. The third area of ethical issues concerns the development of the *interaction of genomics and obesity in particular*, such as the uncertain use or the misuse of information and the failing regulation of health claims, protection of privacy (input, use and sharing of databases) and uncertainties about personal and social responsibility.

Health and Food

The first main area of ethical concern relates to the relationship between food and drugs. Although there has always some supportive overlap between the two (see the

case of food in curing diseases), in general the distinction until now has been rather strict. Food is freely available and chosen for all kinds of cultural and social reasons (beside because of the sheer necessity of giving energy to the body), but drugs are available only on prescription. Food has important social and ethical aspects, and most people do not think exclusively about their own health when making food choices (Komduur et al., 2008). Eating is an ongoing concern that determines everyday life and around which many activities of daily life are arranged. When health is perceived as the only motive to choose a food item and a food item is exclusively seen as a medicine, it would reduce the full meaning of eating and daily life. In tackling obesity with a diet, food is indeed mostly seen as medicine, which means that the ethical implications of the blurring of these important cultural, political, personal, social and scientific distinctions should be addressed.

Public and Private Health

The second main area of ethical concern involves the interaction of genomics and obesity, ethical issues concerning the relationship between public or social health and nutrition, and the increasing prominence of personalized or individualized health and nutrition (we will expand on this theme in Chapter 13). Many argue on the basis of ethical and empirical arguments that a population-wide or public health nutrition and obesity policy should have precedence over an individualist health approach. These arguments are based on efficacy or on ethics. Moreover, they argue that personalized nutrition and health care have negative collective effects. If everybody in the West only wants personalized care, a danger arises that the public health system will be seriously damaged as a result of a personal/collective dilemma (O'Neill, 2002). We run the risk that the medical and food problems of the poor in the West and the South will be neglected because the richer people will all choose their own personal health project. Because of these enormous collective effects, personalized nutrition is not only a personal decision made by the individual, but it also affects the entire population. For instance, it is a well known fact that socio-economic status (SES) and health expectancy are strongly linked. The rich always have more opportunities to take care of their health than the poor and therefore have a longer life expectancy. International public health aims at improving health at a population level. The World Health Organization has been criticized for failing to distinguish genuine health risks from personal lifestyle choices, for example when it refers to a tobacco-related 'epidemic', as if cigarette use were a contagious disease like malaria. Should personal responsibility for health be taken into account in setting the agenda for public health, or does collective responsibility have a role to play?

Personalized Nutrition: Ambiguities

The third main area of ethical issues concerns the development of the interaction of genomics and obesity in particular, such as the misuse of information and regulation

of health claims, the protection of privacy (input, use and sharing of databases) and personal and social responsibility. Also, issues related to communication about personalized services and products, such as claims and informed consent, need to be discussed. Preparation for optimal consumer protection brings up issues regarding intellectual property/equal access. On the level of food choice, identity expression and the roles of food other than for staying healthy are complex ethical challenges. As one can conclude from the article in *De Telegraaf*, quoted in the first chapter, the notion of personal responsibility for health is vulnerable to intentional manipulation by self-interested or commercially interested parties. These challenges can be classified as 'ambiguities', and we will address them in greater detail in Chapter 15.

Of course, these three areas interfere with each other. How far food should be connected with health considerations, or even identified with health, is both an issue for collective consideration and a personal affair. The issue of responsibility must also be considered in these three main areas. But some issues (like those in the second area of ethical issues) involve more individualistic concepts, like informed consent, autonomy and protection, while others involve more collective ethical concerns, like trust and justice. We will come back to these concepts in this chapter and in Chapters 13, 14, 15, and 16.

How do the Three Areas of Concern Interfere with the Four Trends?

Prevention: Food and Health

When food is conceived as a way of preventing potential threats to health, it can be seen as a drug. This entails the risk that food will loose its other, equally essential characteristics, i.e. its social, aesthetic and cultural functions. In food studies, a distinction is made between the physiological, aesthetic, communicative and social functions, the cultural function and the moral function. The food we eat says something about our sophistication (aesthetic meaning), it has a function in the initiation and maintenance of social integration in the group (the meal as communication – social meaning), and it serves to identify status differences and differentiation between groups (cultural meaning). Lastly, what you eat tells something about the kind of person you are, about the type of life you wish to lead, and of course about the fair or unfair distribution of wealth (moral meaning). The physiological function relates to strict survival, concerning the body's minimal needs in order to maintain itself.

These functions are present in different proportions in different food styles. As to the aesthetic function, many modern-day consumers do not regard the aesthetic aspect as most important. In some eating cultures, such as the dominant eating culture in the United States, food is considered mainly for its health qualities and not as a product to be enjoyed. The influence of the food sciences is one reason for this, but most likely a deep-rooted Puritanism is the principal reason for the success of this influence. However, taste cannot be suppressed altogether.

In the cuisines of other cultures, such as French and Italian, the taste function is dominant. Social food studies have supplied a flood of data and theories to show that taste is a socially determined factor that is dependent on the place and position of the consumer in the social network (Bourdieu 1984; Douglas, 1996).

The social function means that individuals come together and confirm their mutual relationships during meals. Food is part of the cultural lifestyle in which people grow up, from which they may later distance themselves (or not) and derive their identity. Societies without such cultural lifestyles and formal and informal relationships are intolerable.

Both the quantity and quality of food products serves as a means of communication, as the sociologist Mary Douglas (1921–2007) has emphasized. The quantity, for example, can indicate how hospitable someone is and to what extent others can count on them in times of food scarcity and other needs. Large food quantities imply a hospitable, open and uncomplicated meal structure, such as in the traditional American cuisine, where in principle anyone can sit down to eat at any time of the day. With small quantities, cooking can be very exquisite, fewer people may be invited, and the sequence of courses is more regulated (Douglas, 1996). French cuisine is a good example of this approach.

Eating much or little can have the same function. Eating much can be a sign that you appreciate the hospitality and are prepared to do a favour in return. That is why diet rules established by nutrition specialists in the United States are ignored so often. An altogether different example is the Japanese rice culture, which confirms formal and hierarchical relationships and is an expression of such relationships. A dinner with all sorts of rice products, including sake or rice wine, can be a formal theatrical performance in which positions are sounded out or confirmed.

The cultural or cultural differentiating function involves groups distinguishing themselves from each other through the consumption of specific foods and avoidance of others. This function is all too often forgotten by overenthusiastic ‘foodies’, who think that eating together is – by itself – enough to unite people. That is what Mintz claims: ‘The way bread tastes, the way dough is prepared and baked, unites people culturally’ (1996, 97). But the taste of bread and the method of baking also serve to differentiate people from each other. Bourdieu (1984) was the first to analyse this differentiating aspect. In a less stratified, more egalitarian society it may be less developed, but in societies with significant differences in rank and social class it can lead to an enormous variation in cuisines. New food products, where it is still unclear how these can be integrated into the existing nutritional views, often lead to great cultural controversies.

Food is produced and consumed within an extensive network of production processes and social links (Atkins, 2001). Because the consumption of food is such an everyday and repeated occurrence, it is closely associated with all sorts of meanings and functions. Furthermore, the consumption of food is a quite intimate, daily happening that is difficult for outsiders to observe directly. It has great emotional significance: meals are one of the extremely vulnerable and valued meeting points where informal relationships are intensified. The consumption of food is also a focal point at formal occasions, such as the dinners of political authorities or company managers.

Table 5.1 Some of the differences between food and drugs

	Food	Drugs
1. Side effects	Not accepted	Accepted
2. For whom?	Everyone	Groups of patients
3. Choice	Multiple reasons (lifestyle)	Health reasons
4. Time taken	Entire life	During illnesses
5. Delivery	Freely available	Over the counter/prescription
6. Activities	Shopping, talking, preparing, sharing	Taking pills
7. Testing	Safety not efficacy	Safety and efficacy
8. Production	Food companies, farmers, (open production systems)	Drug companies: closed lab
9. Responsibility	Governments and food sector	Physicians, drug companies, governments
10. Trust	Low trust in sector	Sector trusted

Food itself is also very closely linked to emotional meanings. Take taboos, for example. Names that we give to groups or to people of a specific nationality often refer to an alleged distinctive food: the French are called frogs, Germans are krauts, the Dutch cheeseheads. Medicines are not associated with these properties; for that reason alone the two can never be identified with each other.

In general, the distinction between food and medicine until now has been rather strict. The most important distinctions between food and drugs are located in the dimensions of personal lives, culture, politics, organizations and market forces. First, food is for everyone, drugs only for the diseased; food should not have negative effects, because of its lifelong intake, and drugs sometimes have acceptable negative effects because of their temporary intake; food choices have multiple reasons and drugs only one (to cure or to protect); food is freely available and drugs only on prescription; and finally, food is not tested for efficacy, but only for safety, while drugs are tested for efficacy and efficiency. If food is indeed becoming medicine in a preventive way, it could be that people can expect to have side-effects from eating; they are expected to choose their food only for health reasons; they should consult their physicians before eating and would have to learn new types of behaviour that reallocate responsibilities, duties and rights in a fundamental way. People will have to deal with the blurring of these important cultural, political, personal, social and scientific distinctions and their ethical implications (Korthals, 2004; Table 5.1).

Individualizing in What Sense?

Personalized Dietary Recommendations Based on DNA Tests and Biomarkers

One of the most famous – and notorious – potential applications of nutrigenomics is personalized dietary advice based on one's personal DNA; a DNA test might reveal susceptibilities to certain lifestyle-related conditions (Chapter 8). Genomics

research on obesity covers also research on genetic testing that might be used to predict the susceptibility to certain dietary-related conditions. However, even in this research field, one is confronted with two of the three discourses on obesity. On the one hand there are researchers like Jeffrey Friedman, who believes that most of the variance of obesity is due to genetic factors (Friedman, 2004). On the other hand, one can find proponents of the Environment discourse, like Roth et al. (Roth et al., 2004) acknowledge genetic factors, but emphasize the importance of other factors such as expenditure due to physical activity and pre-natal influences.

The development of biomarkers is the second potential application of nutrigenomics, implying measuring mRNA and proteins that are formed as a result of a diet and their dynamics. With the help of these biomarkers one can detect in how far certain vulnerabilities develop into 'pre-diseases' due to lifestyle-related conditions at an early and still reversible stage. On the basis of these findings nutritionist could give recommendations on a change in life and food style of the consumer that can delay the development of these pre-diseases.

Both applications are still in their infancy (see Chapters 8 and 14), and it remains to be seen in how far the research produce reliable products in the end and in how far the services connected with them will be established. However, it is important to note, that the different discourses (constellations) on how to frame obesity are also present in the field of genomics. It is therefore not a clear cut case that nutrigenomics automatically will lead to personalizing and individualizing of responsibilities concerning health care.

The Idea of a Gene or Health Passport

This idea appeared in the mass media in several countries simultaneously. In particular, health scientists talked enthusiastically about putting all the genetic data of a person on a chart, which was mostly thought of as an equivalent to a chip card used by companies and public services, which would also be connected to a system that could give recommendations for behaviour and food. These genetic data were not just innocent data, but were indeed seen as the actual constitution of a person, giving information about what risk people have in the short and long term regarding their health. The recommendations that were considered should therefore also be recommendations in the sphere of lifestyle, such as what to eat and when to eat, when to exercise and how. In fact, genetic data typical for a person (the personal genome) also include information about genetic disposition for alcoholism and risks for obesity, cardiovascular diseases and other life-threatening diseases.

In the 1990s, those ideas were generally received quite positively, and DNA companies had already begun advertising some initial examples of the gene card. Insurance companies saw advantages in the device, and real estate agencies, employers and health services organizations spoke about the benefits. However, this was only the beginning of the story of the genome card, and in Chapter 14 we will continue with the later phases of its development.

New Products

In addition to this genetic testing aiming at giving recommendations about lifestyle and nutrition, many genomics researchers, like German and Watzke (2004), go one step further and foresee personalized foods. They predict the development of foods that contribute to healthy lifestyles and foods designed for different metabolism types. Functional food to counteract obesity in particular could be, for example, foods that increase satiety, or that block fat and sugar intake by having molecular constellations that prevent this type of energy from being absorbed and used. It could also be food that maximizes insulin sensitivity and prevents diabetes, such as food with a low glycaemic index). Finally, other foods besides coffee (with caffeine etc.) could perhaps be invented to increase energy expenditure.

New Risks and Uncertainties

Genomics gives a boost to new constellations or balances of risks, uncertainties and benefits, both in a social sense and in a more medical sense. With genomics different futures are possible which is one the first uncertainties. Socially, it can contribute to making established professions superfluous, or at least put them under pressure to change their practices, like those of dieticians and general physicians. It also gives new tasks to professions in the food sector, because they are becoming more responsible for the well being of their clients.

Mostly, these professions are not ready for these changes, which means that they are ill-adapted and that there will be friction and conflict regarding the particular responsibility of these groups. It also implies that in case of emergencies there are many uncertainties about what has to be done by whom.

The new risks therefore not only concern wrong or immature medicinal outcomes, but also unclear and ill-adapted social norms, values and regulations. The other side is that the newly created situations also create opportunities for new groups to acquire new positions and to be confronted with challenges. The benefits can be very uneven.

Uncertainties lie at the heart of the connections between genomics and obesity, and this initially concerns the fact that relationships between diet and genetic profile are so incredibly complex and difficult to clarify. In addition, it is rather difficult to test the health effect of nutrients, and therefore to test the effects of certain diets and products on health. It is hard to define the area between illness and health (see Chapter 8). Nutrients have to interact during a stage at which the body does not yet show any signals of illness. Moreover, many prediseases simply vanish after a certain period of time due to the recovery potentialities of the body.

It is not only that risks abound, like the now established connection between smoking, intake of Vitamin B and increased risk of lung cancer. Also, ambiguities are quite common. For example, two glasses of wine per day could increase

the risk of breast cancer, but reduce the risk of developing cardiovascular disease. One nutrient can be healthy for the heart, but can also be detrimental in relation to cancer. For example beta-sitosterol, which is found in soy and coconut oils, competes for cholesterol uptake in the intestine, but it also undergoes conversion by gut microflora to androstenedione, a precursor to oestrogen. Decreasing cholesterol uptake could benefit heart health, but it is also suggested that the level of oestrogen is a risk factor for breast cancer (Kaput, 2005). Another example is the role of a gene that increases the amino acid homocysteine, which enhances the risk of vascular diseases, but simultaneously protects brain cells against dementia. For bearers of this mutant gene, there is a positive correlation between small doses of folic acid in the blood and the protection of brain cells (Durga, 2004). The latter study showed that the same gene that increases the 'dangerous' amino acid homocysteine (and which gives rise to low blood levels of folic acid), also has a positive effect on protecting brain cells against dementia. Durga argued that public health policymakers faced with the decision of whether to fortify the national food chain with folic acid should wait for the large trials to report their findings on the effects of folic acid – alone or in combination with other B vitamins – on cardiovascular disease and dementia. The operations of the genome and the genome's interaction with nutrients have turned out to be more complex than previously thought. Interactions between genes, enormous numbers of genes reacting to a single nutrient and opposing reactions of genes triggered by the same nutrient have resulted in abundant challenges for nutrigenomics (we will come back to this topic in Chapter 15).

Nutrigenomics will probably (and hopefully) not give rise to fears of serious risks like the ones implied by Frankenstein processes. However, professionals, policy makers, patients and consumers of nutrigenomics are confronted with many ambiguities and uncertainties. Most of these ambiguities, paradoxes and uncertainties are not covered by the usual definition of risk – magnitude of harm times probability – or by the term 'incomplete information'. People can usually comprehend the uncertainties, but assessing these uncertainties is something different. This does not depend on more information but, as we will show later, on ethical strategies, standards and values, some of which must still be created and established.

The complexity of multifactorial prediseases and other interwoven complex causal relationships between genetic factors, -omics factors and the environment (lifestyle, social context) confronts ethics with the necessity of transforming itself from a 'taken for granted' discipline to a 'searching and experimenting discipline'. Ethics can no longer take a certain scientific discipline like genomics for granted, as was done until now, because the science itself is constantly changing and taking new direction without really finishing its current pathway. We address the ethical implications of these uncertainties in several chapters, in particular in the chapter on scenarios, Chapter 7, in Chapter 15 and in the conclusion. In Chapter 7 we distinguish three scenarios, taking into account this fundamental uncertainty: can genomics produce effective tests that allow preventive measures to be taken against obesity? Or is genomics able to do more, and can it produce cures? We return to this problem in Chapter 15.

The Dominant, Existing Ethical Vocabulary of Autonomy

Genomics has much to offer, but it also entails risks. These affect both healthcare and food. The borderline between the two areas is becoming increasingly porous–thanks to genomics. This section outlines several of the risks involved by distinguishing between problems that arise on the levels of the individual, of organizations and of society as a whole.

Food production and consumption have become so remote from one another that *individual* consumers have become unfamiliar with the methods for producing food, and thus have little say about the quality and variety of their diet. Agriculture and food production have long been supply industries. There are initiatives to give the 'informed consent' of consumers a more prominent place in food production. But before you can consent, you have to know what is going on, what is possible and what your practical options are, which most individuals do not. Moreover, the critique on the limitations of this concept (Chapter 2) can also be applied to food (consumption).

Foods developed by genomics will give more priority to the individual. The same is true for demonstrated links between food and health. Food scientists and journalists recognize these individualizing effects of nutrigenomics. Nutrigenomics focuses on the interaction between food components, especially micronutrients, and the unique molecular genetic profiles of individuals. Personal DNA maps will allow a much more specific determination of sensitivities. All these implicit normative assumptions too often put the onus to behave responsibly on individuals. It can be a way for other collective actors, like governments or companies, to shed responsibilities that they are in fact much more capable of bearing than individual consumers. How desirable is this type of individualization? Individuals are isolated from their social environment, while for most people eating is embedded in social contact with family and friends. Wives and husbands determine what their spouses eat, and mothers influence the cooking habits of their children. If scientific experts or DNA profiles become decisive for the choice of what will be eaten, this link between the generations will be lost.

Another problem involves the enormous uncertainties relating to the scientifically demonstrated links between, for instance, a given gene expression, lifestyle, eating style and personal diet. The individual is placed under increasing pressure to decide, but there is no clear basis for good decisions. This insecure, individualized way of coping with one's inadequacies is aggravated if society accepts and promotes only one value as the ideal for a good life. One's body is then seen as a mechanism of continued existence, and not as a source of life's enjoyment.

On an *organizational* level, in the network of companies and organizations working in the food industry, there is no independent body that evaluates the claims made for nutrigenomics or that screens the corresponding functional nutrition for possible overdose effects or for the problem of accumulating different effects. Moreover, there is no independent quality control, and any unscrupulous operator can market health products with unverified claims. In the least suspicious case, claims about a reduced risk of cardiovascular disease, for instance, are simply unverifiable; the

situation is worse in cases where the food component contributes to an overdose of chemicals derived from plants (such as vitamins A or D) or to the accumulation of different effects in certain population groups. The proliferation of unverified claims is reinforced by the enormous influence of private companies in this industry.

But the production and sales of thoroughly tested products is also risky. Perhaps different versions of products will be produced for different population groups, depending on the risk profile of the groups. Consequently, different types of broccoli, rice or orange juice will sold in the shops. But can these different flows of food products remain properly separated? Who determines who is liable if people eat food that their DNA profile says could be harmful?

A final problem relating to the systematic transfer of risks is the lack of a monitoring system that draws attention to, and evaluates, the negative consequences of genomically determined foodstuffs. Most Western countries have a network of institutions involved with the introduction and sale of medicines, but this network is absent for food products. In the case of genomics-based foods or food components, there are special risks involved in their mutual interference and interference with medicines.

One *social* risk is for consumers and producers to focus on food solely for health and enhancement purposes and to ignore the other functions of food: if a diet consists solely of health food, the diversity in food styles is lost. The aesthetic, social and cultural functions of food are also lost. Food says something about the type of person you are, the kind of life you consider desirable and about whether or not wealth is fairly distributed (moral meaning). Recognizing these different meanings implies a distinction, pragmatic or otherwise, between food and medicine. If this distinction is not made, and food is seen solely as medicine, society loses an important hub for informal contacts, for instance the shared meal.

Ethical Deficiencies of Individualizing Strategies (Moralizing or Not)

An important pitfall in the ethical discussion on high-tech developments such as genomics is the frequent reference to individual freedom of choice. For the last 20 years, the emphasis on freedom of choice in Western countries has been closely associated with the dominance of market thinking: freedom of choice is often equated with consumer behaviour on the market. Moreover, even when more collective processes are taken into account, like trust in companies, this is often conceptualized from the standpoint of an individual's relationship with a company (see for example, Lagerspetz, 1998, citing Luhman, 1989). At present, a person's freedom of choice is seen to be subject to only one limitation: your freedom may not be exercised at the expense of the freedom of others. Freedom of choice and not doing harm belong together.

The positive aspects of the principles of freedom of choice and of doing no harm should not prevent us from critically investigating the inadequacies of this approach. It is plausible that the initiative behind new types of positive eugenics will not lie

with the government, but with parents who want the best for their future child. Like a poorly functioning body, a defect in intelligence or appearance is a substantial handicap in social functioning. And surely we all have the right to seek the best possible starting position in the battle for social success? We can already hear future proponents claiming that it is hypocritical of us to suddenly want to set limits on the pursuit of perfection.

In day-to-day activity, the principle of doing no harm works reasonably well. But it works considerably less well for reflecting on new technology, where it can lead to 'organized irresponsibility' (Beck, 1986) due to the clash between individual responsibilities and collective outcome. The advantages of a new technology are usually individual, tangible, direct and certain. However, the imaginable harmful consequences of a new technology – think of environmental problems – are usually collective, abstract, long term and speculative. That means that there is a lack of balance in the discussion of pros and cons of new technologies; people who benefit from them enthusiastically extol the advantages, while it is questionable whether the disadvantages find spokesmen.

Another problem relating to the freedom of choice is the context in which this choice is made. One may well feel very strongly about freedom of choice, but if the people involved have or are given no insight into the real choices, choosing becomes a gamble or a surrender to the advice offered by experts, which is often contradictory. The latter prospect is particularly likely for new technologies, since non-experts hear only part of the story on the long-term effects. In the area of food, for instance, people's freedom of choice is hampered by the enormous gap that exists between consumers and producers.

When we seek ethical norms to guide the development of gene technology, it is necessary to pursue an open discussion of this asymmetry between individual, short-term interests versus collective, long-term risks, and a discussion on the conditions that are needed for freedom of choice to lead to satisfactory results. In the context of large-scale technological developments, we cannot be satisfied with a notion of liability that is tailored to individuals and the everyday practice in which they exercise their individual freedom of choice.

Innumerable debates are taking place on this topic in Europe and in the rest of the world. Yet few ethical questions are being raised in the grey area between pharmaceuticals and food in which nutrigenomics operates, and there is certainly no debate on the liability and accountability of those directly involved. Future debates should not focus on assigning blame, but on probing our way toward a clear understanding of what the best methods are to support and guide people and organizations in performing extremely uncertain tasks, such as selecting the next risk group, or deciding on an enhancement of a food.

The Lack of Institutions of Responsibilities

In contrast with the health system, responsibilities and systems of accountability have not been instituted in any comprehensive way in the food system. In fact, no one seems to be accountable and approachable for the general trends in the

interaction between health and food; neither society as a whole, nor health and food networks nor consumers feel sufficiently responsible. These ethical problems at the social, institutional and individual levels are kept as far away as possible from the public debate.

The principle of freedom of choice is dominant in the world of food and health. This provides consumers and patients with a broad avenue for their individual preferences; as long as consumers are willing to pay, anything seems possible. In the world of food, the individual relationship between the local supermarket and consumer (and sometimes dietician and consumer) receives the most attention; broader relationships are not dealt with in any systematic way. The role of other actors in the food supply network receives hardly any attention. Their functions and responsibilities (or better, lack of responsibilities) only become visible when scandals occur. Who manages gene-profile banks? What information is recorded? Who has access to it? How are priorities set for research into links between genes and illnesses and for the regulation of new professional groups who have direct contact with patients/consumers? None of these issues have been regulated. The same applies to monitoring and evaluating of the negative effects after genetically altered foods have come on to the market; there is nobody with monitoring and evaluation authority to call responsible producers to account.

Pragmatist Outlook

The question here is, to what extent are we prepared for the risks and uncertainties that are *also* linked to nutrigenomics? To answer this question, let us briefly discuss elements which would put us in a better position to guide nutrigenomics in an ethically and socially desirable direction. Ethics cannot be a static entity in a technological culture. Technical developments continually reshuffle our ethical routines for acting and perceiving. We would thus do well to think of ethics as a dynamic process where the search for new concepts and vocabularies, rules and regulations, institutions and agreements is at the forefront. The pragmatist question is therefore: how can we do justice to the interplay between ethics and technology without becoming disoriented?

Technology and Ethics

It is characteristic of technological culture that old and respected borders are continuously shifted, breached or abandoned. If it becomes possible to manufacture custom-made people, in whole series if desired, for instance by using genetic modification in combination with cell nucleus transplantation, then this will exert pressure on the boundary between culture and nature. The addition of all kinds of animal tissue could erase much of the border between human and animal, etc. But this does not mean that we have lost sight of all orientation points and thus have lost the capacity for targeted activity. We can still set limits, even if we do so *pragmatically*.

We need not seek essential characteristics or ontological foundations to create borders, nor do we have to despair if we continually risk encountering moral grey areas because of our deficient insight into the true essence of things.

In line with Dewey's idea of the interactive development of technologies and normative beliefs (and that of co-evolution of science and ethics), one cannot reject technologies or fix normative beliefs ahead of time. We need to both unblock and to argue constructively about what we want with genomics.

The Intrinsic Connection Between Autonomy, Deliberation and Imagination

We do not wish to deny the major importance of freedom of choice, but we would like to argue for discussion methods in which the limits to this freedom of choice can be questioned. In the first place, the government and all other interested parties have the important task of dealing with this asymmetry between practical advantages and abstract harms, and of restoring the balance by drawing attention primarily to long-term, collective, abstract and uncertain damage.

In the second place, what is needed is ethical imagination in the form of scenarios on what is possible, desirable and probable. An important category in evaluating long-term risks is the principle of distributive justice. It is primarily a political responsibility to ensure that nutrigenomics does not enlarge current socio-political differences. We present our scenarios on this topic in Chapter 7.

Recognition of the limitations to the freedom of choice principle also requires that we do not too easily equate true autonomy with individual freedom of choice, which is seen as sovereignty (of the consumer). Sovereignty assumes that people are the masters of their own lives and that ultimately others have nothing to say about how a person wishes to lead his/her own life, or about which personal choices a person makes; it must be complemented with *authenticity*. Authenticity implies that the choices that people make, or the way in which they organize their lives, are really their own in an intersubjective way. We must permit each other to exchange ideas about our wishes – about why we want something – instead of cutting off all discussion with an accusation of moralizing interference. Our preferences do not arise in social isolation, nor are they immune to insights and arguments coming from our environment. Public discussion of conflicting conceptions of what constitutes a 'good life' must again become possible. Good questions to start with are: 'should biotechnology really be used to strengthen everyone's position in social competition?' and 'do we really want drug-taking in competitive sports to become the model for nutrigenomics?'

We therefore argue for a concept of autonomy and freedom that systematically takes into account the roots individuals have in the sociocultural life-worlds, one in which health, food and other values contribute to a good life. The different interpretations of food in the context of a good life, expressed in the interplay between eating styles, including a style determined by nutrigenomics, are a political matter that affects society as a whole. In what way can the *societal* field be organized so that that diversity is preserved, so that new styles can arise and so that one or more eating styles are not unjustly eliminated?

Deliberations

Public places are required for scenarios, the connection of autonomy and imagination and deliberation and deciding upon the main course of genomics. It is therefore worthwhile to ask, what features of public places, in particular, are relevant for enhancing the quality of the interaction between technology and normative beliefs?

There are two important conditions here. The first is consultation and public opinion-making about the relationship of nutrigenomics to social value systems and aspects of justice (such as equal access to the system), and the second is that public places allow accountability and monitoring of the main paths that nutrigenomics is taking. Consultation and public opinion-making should be as polyvalent and broad as possible and develop in all directions; accountability and monitoring should produce unambiguous results to ensure transparency and clarity.

Consultation and Public Opinion Making

As to the first condition, public debates on a social level about the ethical implications of technologies are crucial in preventing the trend toward compulsion, division and lack of pluralism. Public debates take place in the mass media, but can also be promoted by the government or other agencies. This could include general discussion forums on the compatibility of health and nutrition technologies on one side and lifestyles on the other; consensus conferences or forums, with or without arbitrarily chosen participants (citizens' forums); or focus groups (groups with representatives of interest groups). These forums or groups would aim to answer questions such as: which values are under attack and which are promoted by the current interaction between technology and culture? But debates should also be organized on the introduction of more pragmatic and instrumental social arrangements such as the question of whether the government should unconditionally support the idea of a gene passport. And what about DNA profiles and the recognition of gene tests and gene banks? Which other eating styles and views of health should also be eligible for government support and certification?

Monitoring and Accountability

As to the second condition – monitoring and accountability – this requires clearly regulated accountability arrangements such as reporting on past routes, reconsideration or renewal of procedures as soon as irregularities are observed or new elements arise, thus allowing new stakeholders to be identified. Serious consideration must be given to setting up an independent (government-established) agency to publicize and evaluate the harmful impact of introducing genetically modified medicines and foods.

The *organizational* network of nutrigenomics encompasses many old and new actors and practices, which are being assigned new responsibilities on one side and are renewing old responsibilities on the other. While traditional, symptom-driven, curative medicine is based on the individual relationship between doctor and patient, genomics and nutrigenomics bring a variety of intermediaries to the fore, such as screening specialists, dieticians, consultants, fitness and health centres, druggists and pharmacists. These can all be assigned a role in screening and processing the results into personalized diets. On the recipients' side, new solidarities and responsibilities arise among patients/consumer groups relating to lifestyle and health, and these groups have a right to a *voice*. They can raise familiar ethical questions such as equal access to facilities, confidentiality, personal informed consent, privacy and far-reaching interference in the daily lives of patients and consumers. Consumers/users and producers can create co-operative networks to ensure a co-creation of technological and normative developments in each link of the chain.

Conclusion

In the age of nutrigenomics, feeding oneself and living well are not easy tasks. Genomics has long-term consequences over very long time spans that will thoroughly change the daily lives of consumers. Furthermore, genomics in general will contribute to a process of individualization, not only due to the different needs of individuals for different genomics-based food and health products, but also due to the fact that some people can be treated by means of genomics-based products and services, while others cannot. Both of these new developments imply new organizations and networks, and new responsibilities for food professionals. Trust in the food and health systems by consumers and patients can only be upheld when food professionals are conscious of these new responsibilities, act in a transparent way, are willing to respond publicly and seriously to the concerns of consumers and respect their rights to access, voice and exit. The right to access entails the obligation of all stakeholders in the genomics-based food and health system to take social justice criteria into account when considering what type of gene-based disease to research; the right of voice entails the obligation to involve the stakeholders as much as possible, not only in public debates, but also in internal councils in the food and health system; and the right of exit entails the obligation to respect people who do not want to be involved in genomics and nutrigenomics, for example those who refuse to have a gene passport.

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Chapter 6
Obesity Genomics: Struggle Over of Responsibilities

Michiel Korthals

Introduction

Lots of agencies, actors and stakeholders are connected in a network that consists of at least three constellations: one that emphasizes behaviour, a second that has the social contexts as its core, and a third that centers on the body. Many actors are responsible and blame each other. Genomics is creating new opportunities and eliminating others: it does not hold individual personally responsible (so it deviates form the first constellations), although it stresses the importance of life styles. To unpack these blaming games, we will turn to philosophies of responsibility. First we discuss the causal theory that stresses the causal connection between an event and an actor in delineating responsibility; subsequently the theory of role responsibility, which stresses the guideline of not doing harm by performing your job according to the best practice, which has been fixed in the past. So both theories are negative (avoiding harm) and retro-active. Thirdly we discuss the theory of public responsibility, which is reacting to new developments in social and ethical acceptable way, even when there are no clear best practices; it is both positive and prospective. On the basis of this theory we answer the question what responsibility does mean, i.e. its content and scope. While role theory stresses being liable or even punishable for risks and dangers, public responsibility theory concentrates on future acts, that enhance trust in the professions vis-à-vis the public. It means that informing the public and stimulating opinion formation belongs as well to a profession. The complicated problems in confused contexts, so characteristic for obesity, like the issue of the many hands, and that of diffusion of responsibility are discussed. Children are more vulnerable than adults, which means that adults have a strong responsibility here. Genomics creates new public responsibilities and new distributions of responsibility, but also new types of responsibilities for food professionals. How can obese persons (adults, children and their caretakers) move on in this jungle of new responsibilities? Who is held responsible/accountable for the causes of obesity, and for its

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remedies? Are the existing ethical vocabularies up to their task: guiding/coaching these radical new developments? Here we will put some question marks between the ability of a thin morality to deal with the challenges genomics poses to us.

Is the current distribution of responsibilities adequate, fitting for the tasks at hand in the new situation, created by the introduction of genomics? To answer this question, we will discern three levels of responsibility: individual, organisational and collective responsibility.

Obesity Genomics: Struggle Over of Responsibilities. Obesity as a Problem for Genomics

New Responsibilities and New Distribution of Responsibilities

There is certainly no debate on the liability and accountability of those directly involved. Future debates should not focus on dispensing blame, but on groping our way toward a clear understanding of what the best methods are to support and guide people and organisations in performing extremely uncertain tasks, such as selecting the next risk group, or deciding for this or that enhancement of a foodstuff.

As we have seen in Chapter 3, we can at least discern three large existing paradigms that try to manage obesity: one directed towards behaviour and with an orientation of individualisation of the problem (with typical products as Slimfast and a large role for the dietician); one directed towards the social environment and with an orientation of politicalisation (with typical products like stairs and bicycle paths and a large role for engineers, Jackson, 2003); and one directed towards the body and with an orientation of biologisation (with surgery as typical product and a huge role for medical experts). In this last paradigm older, more well established disciplines like Genetics (one or more genes standing for one disease), have already positions in the field. Of course there are a lot of professional groups working (all part of the individualizing, politicalisation or biologisation constellation of obesity) on obesity as food counsellors, dietists or surgeries in huge industries (slim fast etc.) or surgery institutes. They are used to certain practices and regulations in the battle to win the support of obese consumers, and they look to these newcomers sometimes with interest, something with fear. All these parties state that they have certain responsibilities and blame others, but not all act in accordance to that. Moreover, not only food and drugs are at stake; in the political practice concerning obesity, social actors like housing and public space engineers are as responsible as well, and do their job in blaming others and putting responsibility somewhere else.

With the rise of x-omics disciplines, new practices emerge, like screening agencies and databanks, and old ones, like the before mentioned, are challenged to take into account the new scientific insights and devices. This struggle over tasks and responsibilities is going on: the playing field itself is changing, although the players are still trying to do soccer. For the consumers answers to the following questions are not very easy, to say the least: Who is responsible for the epidemic? Who is responsible for preventing and curing the obese and what kind of measures should

be taken? Who is responsible for risks, interferences and dangers connected with the different kinds of preventive measures? Moreover, who evaluates the outcome? It turns out that not only institutions matter, but also material things.

Actors and Arguments in the Three Obesity Discourses

In the three here distinguished paradigms the responsibilities are structured in a different way.

Discourse I: Behaviour

According to this constellation, the individual is responsible for his or her own 'fatty' behaviour, and it seems that the large majority of Western countries is indeed blaming the obese. In the Behaviour constellation a lot of money is earned with obesity, for example by the Weightwatchers ($810 mil), Slimfast ($800 mil), Jenny Graig ($305 mil), and Atkins ($100 mil) with its low carb (no bread, pasta) and lots of meat diet. Surgery is a growing business with 50.000 stomach operations a year. According to Shell, 33 billion dollar a year is spent by Americans on these products and operations (Shell, 2002, 4).

Putting responsibility with individuals and blaming them is still the most common practice. Even Critser (2003), although his book is so thoroughly in treating all the systemic causes of obesity, appeals for 'individual willpower' – and the return of gluttony and sloth to their prominent positions among the seven deadly sins – to 'get [us] out of that hell'. According to a (September 2003) representative survey of Survey@, Zoetermeer, 80% of the Dutch population blames the obese themselves, although 37% gives industry responsibility for it, 21% the cafes and restaurants, 17% shops, and only 10% the government. In the US, the same numbers can be read (Elsevier, 4-10-2003). However, interesting is that these figures are age dependent; the younger people blame more industry, but also more the obese; the elder people blame less the obese. Republicans in the USA are proposing a new law, called Personal Responsibility on Food Consumption, to ensure that customers do not sue food companies or restaurants. Philosophically, this position is argued by Burry (1999), Rigotti (2002) and many others. Still, many are criticizing the practice of losing weight as something very inefficient (approximately 90% is after 6 weeks back to their original weight), like Neal Barnard, from the Physicians Committee for Responsible Medicine (http://www.pcrm.org).

Discourse II: Social Environment

Others blame the social environment, which should be taken very broadly, including advertisements, industry, medical professions, buildings and those responsible for our cities.

According to this constellation *governments* have a certain responsibility: they perform obesity supporting measures, like the structuring of the environment in an obese encouraging way, be it through taxation, curbs on exercises or on sports clubs. Critser (2003) mentions how in the early 1970s food prices were rather high and at the other side there was a lot of dissatisfaction in the US with the policy of President Richard Nixon because of the war in Vietnam. So he and his Secretary of Agriculture, Earl Butz tackled the problem. Butz enacted two reforms that had a lasting influence on Americans′ food choices: he eased regulations on corn production, and he lowered import restrictions on basic staples such as palm oil. Together they started a decrease in food prices. Some governments, like the Irish one, are now considering higher taxes on fat. According to The Guardian, in an article called 'Nip'n'tuck on Irish fatties with tax squeeze' (August 27, 2003), the Irish government also proposes curbs on food advertising, better labelling (with tobacco style health warnings), to provide improved advice on diet and to give subsidies on exercises. Many of these measures are favoured by voluntary associations like the Heart Association, and are criticized by the food industry.

Next to governments, mass media are blamed especially for advertising. The British food Standards Agency claims to have proven a link between promotion of food and children's eating behaviour. This study, called 'Does Food Promotion Influence Children? A Systematic Review of the Evidence,' was produced for the Food Standards Agency by Professor Gerard Hastings and his team at the University of Strathclyde Centre for Social Marketing. The market of food advertisement is 340 mil Euro in UK in a year. A second recent report was issued by The Food Commission, 'Broadcasting Bad Health: Why food Marketing to Children Needs to be Controlled' (2003), with extensive proofs of the risks of marketing junk foods by KFC, Burger King, McDonalds and others.

Schools are held responsible as well, in particular because school boards made lucrative contracts with food companies to provide cheap but junk food (Morgan 2003). In many schools there are vendor machines for sweets and other unhealthy food stuffs; fruit and vegetables are not available.

In this constellation the *food industry* is seen as one of the main actors to be held responsible not only for the epidemic but also for preventing the right measures to prevent the increase in obese persons. According to many reports, the food industry enhanced the amount of salt, sugar and fat during the last 20 years (Center for Science in the Public Interest, CSPINET; Food Magazine, 2003; The Guardian, 27-01-2003; American Public Health Association, 2002). In their article 'Patterns and Trends in Food Portion Sizes, 1977–1998', Nielsen and Popkin (2003) showed that fast food portion sizes and energy intake increased markedly. 'Energy intake and portion size of salty snacks increased by 93 kcal (from 1.0 to 1.6 oz [28.4–45.4 g]), soft drinks by 49 kcal (13.1–19.9 fl oz [387.4 –588.4 mL]), hamburgers by 97 kcal (5.7–7.0 oz [161.6–198.4 g]), french fries by 68 kcal (3.1–3.6 oz [87.9–102.1 g]), and Mexican food by 133 kcal (6.3–8.0 oz [178.6–226.8 g])'. Critser (2003) shows that a serving of McDonald's fries 'ballooned from 200 calories (1960) . . . to the present 610 calories.' This is the reason that the American Public Health Association argues that food industry should cut the hidden sodium in food

over the next 10 years. The amount of salt in the food is now so high, that individual reduction by refraining from the salt vase isn't a realistic option according to Geleijnse (2003). In studies on meat, the obesity enhancing factors are also often stressed.

John Banzhaf, a lawyer, who started to earn money with his campaign against the tobacco industry, has now started an 'Obesity Lawsuit Conference' in Boston, blaming food companies. The International Obesity Task Force in its report on *Obesity in Europe: The Case for Action* argues: 'The original WHO proposals … have been systematically opposed by vested interest groups or *those who naïvely suggest that there are no "bad foods" only bad diets, but then accept the mysterious value of "functional foods" and therefore health claims attaching to individual foods'* (International Obesity Task Force, 2002; 12 – our italics). International organizations like the WHO state that 'food and drink is an issue of public health – not just a matter of consumer choice' (WHO, Report 2003, Diet, Nutrition and the Prevention of Chronic Diseases).

This WHO report has been severely criticized by industry which threatens the WHO to lobby with the Bush administration to decrease the American financial contribution (The Guardian, Sugar Industry threatens to scupper WHO). The same happened with Prof. Marion Nestle for her book *Food Politics* (2002); she was threatened from the side of the Sugar Association.

Science is also held responsible, not only by NGO's, but by food scientists themselves. For example Willett states in his positive review of the book of Nestle: 'However, our advice has hardly been consistent. On the basis of unpublished and flawed data, the 1990 U.S. Dietary Guidelines even encouraged midlife weight gain; though this advice was reversed in 1995, it seriously distracted attention from the developing obesity epidemic. And the nutrition community has almost certainly contributed to the obesity problem by conveying the notion that only fat calories lead to weight gain and that grains and other starches can be eaten with impunity.' (Willett, 2002b, 199)

Discourse III: Genes

In the third constellation, the genes are held responsible, which means that individuals and social actors are less or even not held responsible. Proietto, 1999 argues that the more obese people are, the more genes are determining the obesity. It implies according to him that in the case of extreme heavy weights there is no individual responsibility and even no ethical issue. But this last remains to be seen!

The three constellations are more or less requiring policy lines in continuing opposition to each others, which means that they mostly exclude each other with the consequence that the one that looks most easily (pills) are chosen. This is observed by Walter Willett: '. . .even preventive strategies are heavily biased toward pharmacology rather than supporting improvements in diet and life-style that could be more cost effective. . . . An effective treatment of obesity may be an exception

because the adverse health consequences are so numerous and the conditions of being overweight has become the norm' (Willett, 2002a, 698; Allport, 2003)

As a matter of fact, his plea for life style therapies is applauded by the U.S. Preventive Services Task Force, an association group of dieticians. This Task Force says behavioural therapy and high-intensity counselling can yield a 'modest, sustained weight loss' in obese people. 'Eating and exercising are behaviours in themselves and they're behaviours that are difficult to change,' said Dr. Janet Allan, task force vice chair and dean of the University of Maryland School of Nursing.

Genomics and New Actors

As said, genomics covers the sciences and technologies along the pathways DNA takes till finally the organism is built and each x-omics discipline tries to build a strong position around the respective distinctive knot or node of the molecular pathways (genome, transcriptome, proteome, metabolome etc.). Every node gets teams and programs, and that is the way nature (if one may call so the DNA stuff that they are working on), is socialized. On several locations in these pathways, obesity and obesity related issues are addressed. The imbalance of out and input of energy, characteristic of obesity, means that everywhere in the input (intake of food, drugs), the storage, and the output (movement), where genes, proteins, enzymes and hormones play a role, genomics can assist in diagnosing, preventing and curing obesity. Now it is not always the case that the interaction between genes and environment is indeed the main subject of a genomics study. A good example is the study of Podolsky and others, that shows how some SNP's which are directly connected with obesity, are only switched on in persons with low SES (social economic status). A not so genomics example is the study of Bhathena and others on the effects of dietary soybean and flaxseed meal on metabolic parameters in a genetic model of obesity and diabetes (2002). Soy bean diets that in the experiments were fed to lean and obese rats significantly decreased total cholesterol and LDL in both lean and obese rats but had no significant effect on glucose. The influence of life style on rats is difficult to study.

With the rise of x-omics disciplines, new practices emerge, like screening agencies and databanks, food consultants; with the rise of a new type of patients, children, also new professionals emerges. Moreover, internet companies also offer all kinds of screening and medical solutions prescription free (like overweight.com; curvy weight.com). However, the old practices try to acquire new tasks as well. General practitioners, dietists, retailers, school committees and governments are challenged to invent new policies that take into account the new scientific insights and devices.

Compared to the old constellations of Behaviour, Society, and Body, the genomics constellation identifies new actors (winners and losers), new materials, like search and screening technologies, also new biomarkers, to which also new drugs and foodstuff can belong (Hill, 2002). Normatively seen it doesn't blame the individual, although life style is stressed as an important factor. Furthermore, it has

a decidedly future oriented approach, by its emphasis on prevention and its capacity to predict by high throughput technologies the vulnerabilities of organisms to obesity.

New actors are for example prescription free companies (either web based like overweight.com; curvy weight.com or not), searchers for risk groups like screening agencies, food consultants, and new patients like potentially obese children. In general genomics makes situation more complex, because in analyzing the interactions between genes and their environment, a whole chain of factors is taken into account that remains left out in the others.

Suppose that indeed a number of genes are identified that are associated with a doubling of the obesity risk. In order to achieve an improved public health several phases are necessary to develop. First, it is necessary to debate and make decisions about the paramount issues, like in how far a new drug should be developed, in how far screening is necessary and how wide (whole or only part of the population) in order to determine which populations groups are the carrier of the higher risk and finally in how far existing strategies can adopted to the genomics based. Secondly, if screening is seem to be necessary (part of) the population should be screened; probably new organizations have to set up to do this. Thirdly, it is necessary, to devise intervention strategies to the parts of the population that are in particular at risk and to get funding for intervention strategies. The development of drugs and nutrigenomics products like functional foods is also necessary in this phase. Fourthly, risk communication and decision making is necessary, to let potential high risk bearers to understand that they can profit of effective intervention and participate in the intervention strategies. Fifthly, it is necessary that indeed the potential higher risk bearers do comply, by additional strategies and assistance.

With respect to the first phase, this is essentially a policy issue, and politicians and other stakeholders must indeed be convinced of the feasibility of such a plan to engage themselves.

Regarding the second phase of screening of healthy adults in order to identify presymptomatic carriers or patients, this exists only to a very limited extent in most European countries. Breast cancer screening as well as screening for carcinoma of the cervix are the only widespread examples. Implement new types of screening for genetic predisposition of obesity requires new strategies and social organizations. It could be that insurance companies and companies want to participate or are wiling tot stimulate screening, but they will than also become responsible.

Screening should be offered only when an effective intervention is available, and the limited effectiveness of interventions available, should make us wonder whether screening currently is useful at al. It could also be, that based on genetic or genomic research identification of high-risk groups based on family history is more effective. Where databases and biobanks on multifactorial diseases are established, ethical questions are raised on informed consent, although limits to individual autonomy are also debated, as other principles – including solidarity or the recognition that individuals might have to relinquish some control over the use of their own samples and data if it is for the common good (Cambon-Thomsen, 2004). Ownership, benefit sharing and return of results have also been debated, and

access to medical or scientific results by participants is increasingly seen as an issue (Cambon-Thomsen, 2004).

Regarding the third phase of developing intervention strategies against obesity on a population level based on screening of genetic risks, these do not have templates. With respect to the effectiveness of existing strategies against obesity, only an improvement of a few percent appears to be the optimal effect in the case of an intensive strategy that covers both diet wilt low caloric intake and physical activities. The genomics strategy could add to these the use of drugs, although pharmacogenomics is still in its infancy; despite a lot of jubilant advertisements in quality papers introduced Rimanobant is disapproved by the FDA (NYTimes, June 14, 2007; see also Chapter 14).

Funding of intervention obviously is of major importance. In many countries, just a few percent of health care budgets are spent to prevention. If an intervention is cost-effective, funding by insurance companies or national health authorities is worthwhile. For equal access funding is essential. The availability of interventions may otherwise lead to an increase of socio-economic inequalities.

With respect to risk communication on gene-environment interactions these may be more complicated than communication on single risks only. In general, genetic risks may either be interpreted as deterministic or as a personal characteristic that should motivate people to behavioural change. In the case of familial hypercholesterolaemia (FH), a genetic disorder that leads to an increased risk of cardiovascular events, parents of children with FH experienced the genetic condition in their child either deterministic or as something that empowered them, depending on their understanding of the disorder (Senior et al., 1999). If they experienced FH as a familial nutritional problem, they tended to feel empowered, while those who experienced FH as a genetic condition, felt they could not help.

Finally, compliance to interventions is seldom granted. Some of the calorie limiting diets apparently have a very low compliance. The ingestion of drugs may be limited by side-effects.

Who is Responsible for This Development, and Should Take the Lead?

Public Health in many countries is the primary responsibility of ministries of Public Health that delegates specific responsibilities to regional or specialized health authorities.

When indeed genomics is involved in obesity prevention a new role becomes apparent for Public Health Authorities. New prevention offices and centres are probably necessary. Finally monitoring and evaluation of the interventions undertaken should be put in the hands of one independent authority

Al these measures go against suggestions that individual responsibility is the main lead, because that suggestion displaces the burden from manufacturers, advertisers, and government, and put it on the sufferer (Abelson and Kennedy, 2004).

Next to this public health strategy, governments have the possibility to intervene directly in food markets. Wald and Willett (2004) suggest that governments should define standard sizes of portions, and that the cost of larger portions be made the same multiple of the weight. Thus regulation could help to limit dietary intake of hamburger meat, fried chips and sugar-containing drinks. Jacobson (2004) recommends the provision of calorie information on menu boards, banning advertising for candy, soft drinks, hamburgers, and other unhealthy foods from media used by young children, and keeping soft drinks, candy, and other junk foods out of cafeterias and vending machines in schools.

As a result, a struggle over tasks and responsibilities is going on and the battle field itself is changing, although the old players are still trying to do their old play and accuse others. Who is responsible for the epidemic? Who is responsible for preventing and curing the obese and what kind of measures should be taken? Who is responsible for risks, interferences and dangers connected with the different kinds of preventive and curative measures? Moreover, who evaluates the outcome? For the consumers answers to these questions are not very easy, to say the least. For a first try, I will look for philosophical theories of responsibility.

Three Perspectives on Responsibility

In philosophical ethics three or four different types of perspectives on responsibility can be distinguished. Hart (1968, 210–237) distinguishes causal, role, capacity- and accountability responsibility. According to causal responsibility, one is responsible when one is causally involved in the emerging of an event. Falling stones and running waters can be responsible for destruction of property, so can humans. Role responsibility emphasizes the function of someone, like president or executioner, and acting according to certain rules in presiding a community or executing someone. Capacity responsibility stresses the capacities someone has, and accordingly his or her responsibilities; a person with mental retardation has less capacities than someone who is in full possessions of his or her mental capacities. The last perspective considers also the function important but in additionally the wider effects of someone acting. I will in this discussion take together capacity and accountability (responsibility), because being accountable means that everyone has certain capacities, including the capacity to take recourse to the capacities of others and to take them accountable (Korthals, 2004).

Causal Theory of Responsibility

According to the Causal Theory of responsibility, responsibility is connected with the causal relationship between an actor and his or her activities. Only when the actor really is in control of the circumstances, his or her agency, and the activities that are set into world by the actor (only when the actor is free), the actor can be held responsible. It would be unfair to make someone responsible for events if he

or she is not in control of the circumstances according to this theory. If a food product is excessively eaten by someone, the producer can not be held responsible. So, intentionally causing harm is the sole criterion of responsibility. Only if the causal action of certain harm can be traceable to someone, that someone can be held responsible and is liable for the consequences.

Now, as a matter of fact, we do not control lots of the many acts we perform, and there are many circumstances we do not control, or at least that we do not decide about and that determine our decisions (Ainslie, 2001). There are several approaches to this traditional philosophical issue of freedom and determinism. On the one hand there is the determinist approach, that denies all agency (Pereboom, 2002) and consequently talk about responsibilities is in fact superfluous. The obese persons are not responsible, neither are industry or advertisements (Proietto, 1999). On the other hand there is the voluntaristic view (like in the existentialism of Sartre); according to this view the obese persons are indeed responsible for their overweight (Burry, 1999). Finally, there are several approaches that stress the compatibility between freedom and determinism (compatibilism). Kant's compatibilist point of view emphasizes the agent point of view next to the deterministic point of view of the empirical sciences. According to him, freedom and determinism are ways of reconstructing sequences of events; from deterministic point of view do we organize reality according to relationships of (physical) causes and effects and humans are just effects; from the perspective of freedom we view moral agents acting as free causes according to moral relationships between intentions and acts (according to the laws of freedom; Korthals, 2004). Again, the individual persons should be held responsible for their food choices and lifestyles. However, what this perspective doesn't take into account is the fact that intentions, actions and lifestyles are shaped by cultural and social circumstances as well, and that they are neither totally in control of the agent nor totally out of his or her control.

Actions can be caused by something beyond our control, and still we can be in control of them. This makes the perspective of freedom and responsibility more complicated; in fact it urges to reconstruct the distinction between freedom and determinism not as a distinction between two different, excluding viewpoints, but as a gradual distinction, which means that an agent can be more or less free to chose the food, or more or less determined, and dependent on the circumstances.

Role Theory of Responsibility

Connected with this complexity, is the issue that the description of acts, generated by human agents, can vary. Suppose I intentionally open the outside door of my house, and simultaneously deter a prowler waiting in the dark, hurt the kid that was just trying to open the door from outside and alarm my partner that slept upstairs (the so called accordion effect of Feinberg). The social contexts that shape actions and their interpretations, is not taken into account by the causal theory of responsibility. In daily life we normally use a more social theory of responsibility, where causality is less important; when we hold parents, drunken drivers or political representatives

responsible for the actions of their children, their risky behaviour or their civil servants, it has to do with relationships of parental role (care), assumptions about driving or about political roles and not with causal responsibility or the lack thereof.

According to the role theory of responsibility, it turns out that we allocate responsibility to actors depending on social roles and social contexts and not only in how far they are really the cause of certain events or have a conscious determinate say in the coming about of these events. This allocation has everything to do with the normative structure of our societies, and is not only an empirical fact. Now, the social contexts do not supersede causal accounts, but complement them. Intentionally, negligently or recklessly causing harm, by doing certain types of research (remember the Tuskegee Syphilis Experiment) is covered by this concept of responsibility.

There are at least three issues which make role responsibility questionable. First, take the comment of the Challenger director to the engineer who warned for the wacky sealings in the rocket that ultimately caused the catastrophe: 'take off your engineering hat and put on your management hat'. It is often not clear what your role is as a life scientist or engineer in an organisation or society, and I would even argue that some concerns of certain roles (like safety) should override other aspects (like profit or management). A second issue is that even granted a well organized practice of doing science and technology, there is still the issue of the goals of the organisation, its research agenda, its research priorities and its research design as well. Here scientists have some responsibility to society at large as well, that transcends role responsibility, but harbours towards public responsibility. One does have only to recall the actions of Einstein and Oppenheimer in banning atomic bomb testing, or those of Rachel Carson and Barry Commoner in the sixties about the banning of DDT in favour of biodiversity, to see that scientists do have a certain responsibility towards the common or public good, that transcend their particular good when working in a certain organisation and doing their job well (Shrader-Frechette, 1994). If it is indeed the case that events and actions can be caused by something beyond our control, at least professionals should try to be in control of them. A third issue is that roles are changing with the practices of which they are a part. With respect to life scientists, when their practices turn to social life in being involved in obesity producing food stuffs or genomic measures, their social role is changing accordingly; here again there is no causal responsibility, but at least co-responsibility for large scale effects, however to what extent and in which measure?

Pragmatist Theory of Responsibility

According to the pragmatist theory (Keulartz et al., 2002) dualism like that between freedom and determinism or between control versus subjection should be prevented. In stead, we should look for co-evolution of technology and ethics, in the sense that new technological developments are seen as intriguing challenges for common morality frameworks; they do not a priori function as impulses to draw red lines or erect red sign posts. Co-evolution of technology and ethics makes it clear that both change in reacting upon each other; in that sense technologies have a broad ethical

component inside, and ethics is intrinsically connected with technologies; neither of them can be held constant and unchanging. Responsibility is not only at stake when there are accidents or risks: it should be a normal feature of the actions of a practice to reflect upon the social embeddings of its goods in the social world of the end users. The decidedly democratic nature of pragmatism directs its attention to the victims of practices and to their vulnerabilities (Walker, 1998). It implies that the anticipation of negative implications of actions consequences should be considered, and that proactive attitudes to manage them in a respectful way are looked for.

In analyzing urgent ethical problems (indeed, those problems that hurt, not the one that might arise, but are rather far away or science fiction), I use the concept of practices, in particular their interrelationship and their relationships with public debates, consultations and decision making. This concept is very useful because it makes it clear in what way technologies are itself part of social practices, that are translated towards other social practices. Embedding life sciences and their corresponding technologies in social practices means therefore to open up the social practices of science towards the social practices in which they are translated and looking for possible positive connections between these practices and negative, controversial encounters. For example, when genetics really started to use new technologies for predicting and treating certain diseases, like Huntington, patient organisations, hospitals, clinics, and advisory agencies change correspondingly, as well their standards of excellency as well as broader norms.

In looking for all kinds of compromises, new future possibilities (scenario's), we, 'pragmatists', try to de-stabilize fixed frontiers between practices. Practices have values and goals, like standards of excellence, as wells as concrete products, that are measured against these values and goals. When practices change, the norms change as well and this is not only of interest for the practices concerned, but for society at large. Public consultations are than necessary.

The recent developments with respect to life sciences put them into new constellations with other practices of health care and food, in the way that they change these practices as well, and require that many of their traditional standards of excellence and broader norms should be made subject to revision. Because of the huge investments, private public cooperation ('triple helix', Etzkowitz and Leydesdorff, 2002) is more and more common. Regulations that are upheld in the private sector, like patents, are now common in the public sector, sc., the universities, as well. But also other regulations and attitudes are also moving from one public sector to another quasi public sector; health diagnostics, health screening and health advising that used to be performed only in the health sector now are performed more and more in the food sector, although the necessary moral and legal regulations often are just absent.

The three theories of responsibility here distinguished have their partial correspondence to the three types of obesity constellations. It is not that we like the magic formula of three, but this is the result of our inquiry into the different constellations and theories of responsibility. Causal responsibility is in particular emphasized in the constellations Behaviour and Body, while role responsibility and sometimes pragmatist responsibility play a role in the second one, Environment (Fig.6.1).

Main discourse/ counter discourse	Behaviour / beautiful	Environment / victim	Body / ill
Before genomics	Causal responsibility	Role responsibility	Causal responsibility
After genomics	Role/ genetic responsibility	Diffused/ Role responsibility	Diffused/Role/ genetic responsibility

Fig. 6.1 Different types of responsibility according to the three obesity constellations (main discourse and counter discourse) before and after the (successful) introduction of genomics

One should make a distinction between two possibilities. First the possibility that genomics gives a lot of understanding and insight in obesity, but not really an effective diagnosis or even cure. In this case the three types of responsibilities do not change accordingly. The second possibility is the reverse of the first, suppose that genomics indeed produces a successful diagnosis (prevention) and moreover a promising cure, than it is possible that the three different types of obesity constellations imply changes with respect to their corresponding notions of responsibility. However, we must also recognize the first possibility that indeed genomics doesn't produce any results, and that the situation remains as it is before and after the (very partial successful) introduction of genomics. In the next chapter we will go into deeper detail on the future possibilities by sketching several scenarios.

Content and Scope of Responsibility

As said, moral responsibility doesn't always cover what a person controls, but also what he or she doesn't control, i.e. what is happening to her or him. The way people accept that not everything is controllable, determines the realization of their responsibility. This is the reason that one can be called moral negligent even where one has not directly caused harm. The scope of responsibility therefore means that people can be held accountability over the past, the present and the future with respect to certain actions. Responsibility has future consequences: these can be disasters, misappropriations of users, but also anticipating and assessing benefits and losses, not only in a calculative way, but in a deliberative way as well and managing them.

How far can in the future and in space our responsibility be stretched? By increasing our knowledge over future constellations, the knowledge producers increase their responsibility for those future events (Bovens, 1998). In particular knowledge on future constellations and the way they can be prevented creates new responsibilities. This is one of the reasons that bio informatics and in particular in the holistic, systemic way it is done in x-omics (Genomics and all the other branches) has such an ethical relevance.

Responsibilities in particular depend on the technologies used: they have a say in distributing and allocating responsibilities as well. The drugs or food stuffs (the technologies of the first constellations) require different responsibility structures of the firms concerned (like Xenical, Meridia) than surgery. And they address different end-users, which also affects responsibilities. In particular when children are addressed, the situation changes because children are more vulnerable that adults, and need more protection. They at least can't be supposed to give their informed consent or to assimilate the required knowledge.

Problems of Diffusion of Responsibility

With nutrigenomics it is stated that not the genes on their own are causing obesity, but their interaction with proteins and the larger environment. This makes it more difficult to identify a typical locus of responsibility. Shell writes about a 'soup' of various factors: 'The labyrinth of genes, peptides, and hormones regulating food intake is dense and Byzantine, extremely difficult to food or manipulate. Knocking out one or a couple of components of this system with drugs is unlikely to work, because eventually other components step in to take their place (Shell, 2002, 147).' 'What is certain is that an alphabet soup of molecules – neurotransmitters and neuroproteins – is involved in a network controlling the leptin response, and any slips along this pathway can, given certain environmental conditions, fool the brain into demanding more food than the body needs' (Shell, 2002, 119).

The division of labour between the big players, food industry, food professionals and governments is rather uneven, because the food companies earn a lot of money by their products (assisted by advertising companies). The normative framework of the design of their products (see about this concept also Chapter 15) suggests the end users that with energy full products the good life is underway, whereas governments until now only sell a gloomy picture of short, fat and unhappy lives. The food engineers have implicitly or explicitly materialized certain values in the fat products that in particular attract children. When Unilever started its campaign of seven sin ice creams, all children were buzzing around to be the first consumers of the new tastes. The message of genomics adds another aspect. Because so many factors should be taken into account ('the soup'), the end user is disoriented. This production of ethical unbalancing is enhanced by the blurring of conventional distinction between for example sweets and vitamins, which makes food choices still more difficult.

This 'soup' problem can imply that less responsibility is taken. It is a problem that arises when more people are involved without clear tasks; they feel than less

responsible. In ethical literature this is called the problem of the Many Hands and it is all about the diffusion of responsibility. Responsibility for complex problems in complex societies shows all kinds of mechanisms to escape from responsibilities, in particular in contexts of diffused responsibility (Myers, 2002; Smith and Mackie, 2000). Either too many are held responsible or even more simply too many people cause actors to detract from taking responsibility and *social loafing* (social ignorance) takes place. This can also take place in cases where one person or institution is held responsible, with the consequence that all the others do not feel responsible. In this case it looks as if allocation of responsibility is like water: it has the dynamism of communicating vessels, and it thins down when too many are held responsible.

Social Structures in the Soup of Responsibilities

Because of their vulnerability, children should in particular get special attention in preventing obesity; the actors have with respect to them special responsibilities. But how to structure the field in order to prevent the spreading of the epidemic? In cases of social loafing and dilution of responsibility the remedy is to install clear structures of responsibility, to identify the big players in the field and to define the spots where responsible action can make a difference. These big players are primarily food companies, retailers, governments (and governmental agencies), and food scientists and technologists and they can make a difference. Where is the weakest link that promises the most efficient outcome and requires the least efforts? It can be combination of several aspects, of short term and long term measures, of preventive and curative measures, of social structures and material products.

First, the players and who should take the lead. There is one player that legitimately can take the lead in this, that is governments. An epidemic, like obesity, is a public problem: when so many die (30.000 deaths are caused by obesity in England alone) or have to be life long treated for e.g. diabetes II, public losses are at stake. Until now, there are no rules, no codes, no agency, and here governments can do a lot, by reconstructing the room for responsibility to be taken by food companies, by preventing to let escape food companies from their responsibilities and blame others. Governments can do this by encouraging producers and consumers to take their responsibilities, e.g. by giving (research) subsidies for less salty, sugar and fatty products or for food education. But encouragement is not sufficient. Food companies for example are willing to subsidize fitness centers; but they won't voluntarily change the amount of saturated fat, sugar, and salt in their food products, and these are the weakest links. So, secondly, tax measures connected with these ingredients could be a remedy to cut down the amount of saturated fat, sugar and salt. Taxes on these ingredients urge companies to look for alternatives that don't have obese effects, like unsaturated fat, healthier types of salt etc. Thirdly, food researchers have sometimes professional codes, but they don't always take the opportunity to act responsible. So at least public research institutes, even when they engage in

private-public constellations, should do research in and design food products that are healthy, tasty and satiety reducing and private companies should be encouraged to do this. Fourthly, the products. Direction of food products in smaller portions, and with the help of genomics, with satiety reducing ingredients can make an enormous difference. Moreover, these ingredients have the effect that greedy food companies loose their grip, because people will ultimately buy less, in stead of more. The nurture, cultural, aspects can be changed more efficiently: life style changes in the direction of enjoyment of food by eating fruits and home cooking of vegetables are plausible. These require again policy measures by encouraging schools to spent time to cooking and buying good food. However, individual weight control is according to most studies absolutely inefficient, so that strategy is the least attractive (Serdula et al., 2003). Our building environment cannot be changed in short term, but also, governments can encourage to pay attention to better and safer walk- and bicycle paths.

The developments make it necessary to find a new balance on two levels: between free choice and public health, and between healthy and tasty food. The first balance requires a new social network for responsible actors, with a special role for governments in this network: protecting children (ban on advertisements, unhealthy school menus etc) and enhancing responsibility of consumers and producers. The second requires a reconsideration of the function of (food) technology in realizing good life, and in particular of the role of food in our daily life.

Conclusion

Genomics makes the situation for the treatment and prevention of obesity more complex. It makes it clear that monogenic connections, individual diet or obesogenic environment mostly don't work on their own but in combination with other factors, like lifestyles and food patterns. Both the diagnostic and the more preventive tools, from both the human side (behaviour genomics, like appetite control) and the food intake side co-operate with new actors, and reconstruct the traditional allocation of responsibilities. The new knowledge, produced in new practices of researchers, medical and food professionals, connects, delineates and limits responsibilities. The new knowledge also determines a difference in winners and losers, because it enables to identify new groups with vulnerabilities, in particular potential obese children. It turned out that genomics makes the issue of responsibility for the epidemic of obesity even more complex. It requires a new balance between healthy and tasty food. It should be directed to healthy foodstuffs that are attractive for children, but not by sweetening already unhealthy food products. So, greedy food companies should stay at a distance. It could also be a total new direction: with the growing importance of satiety genomics (appetite control mechanisms), nutrigenomics could concentrate on food stuffs that cause satiety. The design that nutrigenomics food stuffs takes is of primordial influence for the future development of this science, and it can enhance or decrease the public authority of science (Korthals, 2004).

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Part III
Futures, Genetic Testing and Enhancement

Chapter 7
Obesity in 2020: Three Scenarios on Techno-socio-ethical Co-evolution

Tsjalling Swierstra and Jozef Keulartz

Introduction

In Chapters 3 and 4 we sketched the current, tension-ridden, constellation around obesity. We saw how three discourses, connected to specific practices and artefacts, competed for hegemony in defining the problem, its causes, its solutions and the main-actors. In this way, each discourse allotted (primary) responsibility for solving the problem to other parties: the obese individual, the state or the physician, as we showed in the previous chapter.

Some place the responsibility for one's obesity squarely upon the shoulders of the individual. It is true, the age-old moral condemnation of obesity in terms of gluttony and weak will has to a large extent been replaced by an aesthetic regime which requests an effortless leanness as a symbol of a highly valued youthfulness. This attitude is no longer openly moral regarding weight-issues, but in its practical consequences it is almost equally forbidding as the preceding Christian attitude. Furthermore, obesity is still treated as a moral issue because of the medical and economic costs the obese person inflicts upon his or her fellows. Others point to the moral perversity that in large parts of the world people starve, whereas in the decadent West people eat themselves to death. These aesthetic and moral judgments, however, are fought by others, who contest the dominant aesthetic body-ideal, question the medical and economic costs of obesity, or point to the fact that many can not be held responsible for their condition because they were uninformed about the risks they ran. Furthermore, this moralizing and individualizing discourse is criticised by proponents of the (socio-economical and material) environment and of the body (or the genes) as the primary causes of obesity.

In this chapter, we want to sketch three scenarios for the ways genomics can be expected to influence and re-shape this constellation. Our methodological point of departure is provided by the so-called *co-evolution* thesis, which holds that technological development and social development mutually shape each other. More particularly, we want to focus on the *moral consequences* of genomics. That is: we

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will try to anticipate the ways existing moral (and political) discourses might change as a consequence of this particular form of techno-scientific progress. In this respect we differ from genomics scenarios like '*Scenarios on Genomics and Society 2015: Priorities for Social Science Research*, A Project for the UK Economic & Social Research Council (ESRC), carried out by the Institute for Alternative Futures and the Centre for Research on Innovation and Competition' and '*Foresight Study on Bio and Health Technologies*, Danish Ministry of Science, Technology and Innovation, (2003'. Of course, these scenarios rest on speculation. But scenarios have aptly been described as a form of *controlled* speculation. This 'control' comes from a diagnosis of the resources, restrictions and patterns that can be detected in the here and now. The present constitutes the bed that determines the flow of the river. What we try to do is anticipate how the river's flow will change this bed in the future. Co-evolution entails that existing moralities, in a broad sense, encompassing discourse, practices and material objects. – as we sketched them in the second chapter – will influence how genomics will affect the ways we deal with obesity. And vice versa, that these moralities themselves are bound to change under the influence of genomics.

Method: Trends, Drivers, Key-Elements, Moral Agnosticism

In scenarios, we can differentiate between so-called *trends*, *drivers* and *key-elements*. Trends are extrapolations of the present that are accepted as highly probable. All the scenarios in a specific study therefore share these trends. Trends usually serve as the non-problematic, implicit background of scenarios. For example, in the following scenarios we quietly assume that the developments will take place in the context of the modern, pluralist, fairly affluent and democratic society typical for the Western part of Europe. In our scenarios we take aging as a trend, as well as the development towards a multi-ethnic society. We have put the influence from foreign countries between brackets.

Drivers are possible developments with uncertain or contested plausibility: it is quite imaginable that they will occur, but it is equally thinkable that they will not. For example: it is still highly uncertain whether genomics will in the foreseeable future result in important new therapies or not. It is also highly uncertain where the public opinion will shift to in the case of a disaster related to genomics. Therefore, these drivers – as dimensions of uncertainty – serve to differentiate the scenarios. Put differently: scenarios are ways of exploring different driver-modalities.[1] In our study we have selected as driver the question whether genomics will only lead to more opportunities for prevention, or also to a cure in the form of a pill. We will see that this driver heavily influences which discourse on obesity will plausibly be hegemonic. Note carefully, hegemonic is not meant as having triumphed completely over the two competing discourses, but as being in the lead and as being able to

[1]Of course, it can be a matter of heated (political) debate whether a development should be qualified as a trend or a driver, because labelling a development as a trend tends to close this development to political intervention.

Table 7.1 Three scenarios of genomics going obese

1. Individual	2. Environment	3. Body
Health as merit	Corporate responsibility and no cure	The liberation of fun

marginalize or integrate the other two discourses. This leads to the following three scenarios (Table 7.1):

A third concept that is relevant in scenario-studies is 'key-element'. These serve to develop different scenarios in a commensurable and systematic way by listing the issues each scenario should dwell on. In our study, we selected the following key-elements:

1. A short account of the rise to dominance of the obesity discourse in question, with special attention for broader ideological, cultural, political, demographic, economic or technological developments that were functional in this process.[2]
2. The ways established morals influence the shape of new techno-scientific developments in the domain of genomics
3. The ways developments in the domain of genomics enhance some parts of existing morality, and discourage others. To be more precise: we will ask ourselves five questions:
   a. which new (im)possibilities does the new technology create?
   b. to what new rights and obligations does the new technology give rise?
   c. how are responsibilities (re)distributed as a result of the new technology?
   d. how does the new technology affect the established distributions of costs and benefits and the moral criteria with which these distributions are justified?
   e. how are existing identities and conceptions of the good life likely to be challenged by the new?
4. Public debate and political strife are bound to exist in the future. So: what shapes will the resistance to the dominant discourse most likely assume? What are plausible counter-discourses?

Finally: there exist different types of scenarios for different goals (Van Notten et al., 2003). Our goal here is to explore in the most open way possible the dynamic interplay between genomics and morality in so far both touch upon the issue of obesity. Because the moral discourses on obesity are themselves the subject of the scenario studies, it is important that we do not restrict our moral imagination beforehand by positing ourselves squarely in either one of these moralities. Instead, we have strived for a kind of moral agnosticism. Not because we are agnostics, but as

[2]An idea we put to use here is that ideological and cultural changes on quite separated issues are likely to pave the way for ideological, institutional and/or practical changes in the field of obesity/genomics. In evolutionary biology – and in Science and Technology Studies – this phenomenon is referred to a 'path dependency'.

a methodological stance to open our minds to whatever moral change the future of genomics might have in store for us.

The three scenarios are written from the perspective of the hegemonic discourse. The year is 2020.

Scenario 1: Health As Merit

In the first decade of the 21st century obesity became finally to be seen for what it in most cases is: a matter of individual moral failure. This was partly the result of broader political and demographic trends, partly the result of the further development of genomics.

By this time, politics had for several decades chosen to deal with complex social issues by privatising them, delegating them to the increasingly competent and vocal citizens. Collective problems can best be met by motivating individual citizens to change their behaviour. Politicians learned that the best solution in politics is usually: *stimulate individual responsibility*.

The existing system of collectively financed healthcare was finally denounced for what it was: ineffective, inefficient and far too costly. The costs of medical care soared, as a result of the constant invention of new, and invariably expensive, medical technologies. An erosion of social solidarity was the result. This trend was enhanced by demographic changes. Because of the aging of the population the costs of healthcare soared. More and more working people began to ask themselves why they should pay for the health of aging baby-boomers. Especially members of ethnic minorities – who by now constituted a considerable part of the work force – felt little or no obligation towards this generation. The solution was found in dividing up healthcare in two compartments: the government restricted collective financing to simple basic care, and if one wanted more expensive treatments, one had to pay for them oneself (directly, or indirectly by taking a private insurance). In this way, the individual patient was made more directly responsible for her own healthcare.

This general trend towards individualisation of healthcare was considerably stimulated by the development of genomics. First, the progress in medical and nutritional technology created new opportunities for diagnosis, prevention and treatment. Second, genomics made it possible to tailor diagnoses, advices and treatments to the individual and her genetic make-up. This helped spreading the notion that medicine is basically about and for individuals. Unfortunately, both new opportunities helped raising the healthcare costs. Prevention may help saving money in the long run, in the short run is demands extra investments. And the new tailor-made drugs and functional foods were more expensive than the older ones that had been produced in bulk.

Because obesity is a matter of great medical, economic and also some – why deny it? – aesthetic importance, billions and billions have been spent on genomics research conducted in this area. This at least is an example of how an important social value has determined the research agenda of genomics in the last two decades.

In the first decade of the new millennium our scientific understanding of the multifactorial causes of obesity increased rapidly. Obesity, genomics researchers have found out, is a multifactorial infliction: genes influence but *do not determine* this condition. Furthermore, genomics enables us to foretell who runs a higher risk to experience weight problems later on in life. There is no easy cure, but this is of limited importance because prevention – and losing weight – *is* possible.

Politicians at the time were above all concerned about the soaring costs of our healthcare. They were definitely not waiting for scientists with new, costly plans. But these scientists pointed out that for the foreseeable future genomics would generate hardly any new drugs. They stressed that most common afflictions were multifactorial in character and too complex for a simple 'pill'. Such a pill is unnecessary anyway, thanks to genomics, we can now match forms of dieting and exercise with everyone's individual genotype. To acquire a healthy bodyweight, one simply has to change one's patterns of eating and exercising. For all but a few exceptions, bodyweight has truly become a matter of the free will. Also, the politicians realized that a good obesity-prevention program would lower the intake of medication – which the collective often had to pay for –, even if the program would stimulate more expensive diets – which people had to purchase privately. They embraced the obesity-program because they hoped a shift from medication to nutrition would help reducing healthcare costs.

The geneticists pointed out that individual responsibility could only become successful if individuals could make well-informed choices. But when the *Gezondheidsraad* (National Health Council) advised in 2012 that everyone should be regularly tested for gene mutations, politicians rightly protested. It is everyone's own responsibility to take care of one's health, so people can be asked to pay for these tests themselves. If necessary, they can visit a doctor, who nowadays spends a large part of her time in giving individualized lifestyle advises to her patients. And instead of prescribing medication, she prescribes (or discourages) specific food. The government can therefore restrict itself to funding a publicity campaign urging people to take such tests and to visit the doctor. As a result, most people have now included genetic tests in their medical insurance. Only the really poor can apply for a free genetic test every 5 years and visit the doctor for free advise. However, if they choose not to obey the prescriptions of the doctor, they forfeit both these rights.

The new genetic knowledge and the connected opportunities for prevention and treatment have effected major changes in how we think about and deal with obesity. Thanks to the progress of genomics, public consciousness of the importance of prevention was considerably raised. By warning the potentially obese individually, genomics has motivated many to change their lifestyle. There are of course always those who are unwilling to change their behaviour, but now at least they have to accept responsibility for the consequences of their misconduct. They can no longer hide behind the worn excuse that they did not realize the consequences of their conduct.

Genomics has put a stop to the widespread practice of reaping the benefits of your behaviour individually, and then letting the collective bleed for the costs. Thanks to genomics, we now realize obesity is a lifestyle disease, which means that it

is ultimately self-inflicted. Understandably, more and more people started to ask themselves: why pay for other people's obesity related diseases, when these could have been avoided by adopting a healthy life-style? You misbehaved, then you suffer the consequences. That is only fair. The *possibility* of prevention turned into an *obligation*, at least if one wanted to claim solidarity from others. The right to ask for help has been made dependent on this obligation of self-care. And if one wants to exercise this right, society has the right to first check the facts. For the obese this means that their private life comes under scrutiny at the moment they ask help. Furthermore, genomics led to the proliferation of different risk-groups. Why, many asked themselves, should we show solidarity with people with whom we don't share the same medical risks? Let the potentially obese organize their own solidarity within their risk-groups.

It is also interesting to see how genomics affected people's self-image, as well as their conceptions of the good life. People have become more aware that everything they do affects their health, positively or negatively. There is a growing sense that we have a duty to take care of our own health. This implies that we now scrutinize everything to do with eating and exercising. It is now generally considered irresponsible to live carelessly. It is praised as virtuous to calculate long-term risks beforehand, and to command the willpower to take the necessary, sometimes unpleasant measures. In the last two decades, genomics has proven to be very effective in changing how people live. Much more effective, one has to admit, than over two and a half thousand years of (virtue)ethics.

All in all, genomics helped to accept that one's body weight is a matter of individual, moral responsibility, and it added significantly to the old obligation to take care of oneself. However, although true in most cases, there are two groups whose position is more complicated. First, low-income and low-education groups have proven to be slow to pick up the new genomics information, and to change their conduct accordingly. The information lies there waiting for them. Every citizen has the right to free information about her genetic make-up, so as to enable everyone to live responsibly. But these groups seem by and large uninterested: they lack the motivation to get this crucial information about themselves. However, they will learn in the next few years that society is no longer willing to pay for those who recklessly inflict damage upon themselves. If they are not motivated by their own health to acquire the relevant information, maybe the consequences for their wallet will provide the necessary stimulus.

Another group that cannot simply be held accountable for their body weight is the minority of the pathologically obese for whom no behavioural change seems to work. The 'certified pathologically and incurably obese' of course deserve our consideration. However, to prevent simulators from trying to qualify as pathologically obese and reap all the benefits of being officially sick, everyone has to subject to a strict behavioural regime before one is allowed to apply for help.

Most of the counter discourses on obesity that existed in 2000, gradually petered out thanks to the progress in genomics. Of course, even now in 2020 some people persevere in their denial of individual responsibility for one's weight – notwithstanding the clear findings of genomics. For example, there still exist small subcultures

that hold the obese body in esteem. These protest against the aesthetic standards of the lean and mean body. But since the increased possibilities for preventing obesity resulted in an increased social pressure to actually do so, obesity has become much rare. This has reinforced the 'official' aesthetic norms and standards. Two decades ago the Body Shop advertised that only a handful of women actually looked like photo models; nowadays it is definitely more than a handful, which makes it harder for the rest to deviate from the ideal that is increasingly becoming a social norm.

The sceptics, who disputed that obese people did not harm their fellow-citizens by raising the collective medical costs, are equally seldom heard of nowadays. In all honesty, this is not due to new scientific findings. Rather, their sceptic arguments lost their point after the individualisation of the medical costs for obesity.

However, in their place a new group has come to the fore, the so-called *bon vivants* who denounce what they see as an intrusive moralisation of areas of life they feel should be left free of moralisation. They protest against seeing oneself as potentially sick and always at risk. They refuse to plan far ahead and say they want to live by the day. They are consequent in that they claim to be willing to forfeit the solidarity of their fellows in the case they become sick eventually. These people are often very young, however. So let us wait and see.

Notwithstanding the overwhelming scientific evidence, we also still find the idea that it is not so much the individual's will that is pivotal in obesity, but her environment. According to this small band of radicals, the government should take steps to change this environment. And of course, they are right in that people do not act in a vacuum. But they are not puppets either! However, what is more important is that these radicals forget that such regulations, although beneficial to some, are quite restrictive to others. What is good for one genetic risk-group can be a quite unnecessary restriction of the freedom of another risk-group. Yes, I am sure that for *you* it would be very beneficial if we would close the elevators in our office. But why should *I* be forced to climb the stairs simply because you are too lazy and irresponsible to do your physical exercise in your own private time? Be honest: even at work no one forbids you to take the stairs whenever you feel so inclined. The only government intervention we need is providing everyone with the necessary genomics information for making informed, autonomous and responsible choices. That is why snack food nowadays has labels a bit like those introduced 20 years ago for cigarettes – only now with the proviso that the danger is relative to your genetic make-up, so the advise is to check your gene-map or ask your genetic advisor.

At the other end of the spectrum, we find an equally small band of radicals holding that it is not the environment, but the biology that is the cause of everything. Some of them think nothing can happen to them because they have 'good' genes – so they eat and drink themselves to death. Others, having heard that they are at extra risk, have become fatalists. They simply give in to what they perceive to be their biological fate, quietly hoping that someday a doctor will appear on their doorstep with a miracle cure. (A rather unfounded hope. An 'obesity pill' is typically something hoped for by the weak and depraved – much easier than dieting and exercising! Happily, private capital has withdrawn to other pharmaceutical sectors, concentrating on more honourable types of medication.) Both groups commonly

suffer under the misapprehension that their genes determine their biological fate. This only shows – again – that a little knowledge is indeed a dangerous thing!

Scenario 2: Corporate Responsibility (The Environment + No Cure)

At the end of the second millennium the influence of the individualizing and moralizing discourse of individual responsibility was already waning. Of course, this was difficult to see clearly at the time. The demise of this discourse was largely due to two separate developments.

For a long time, the rightwing government had firmly believed in the beneficial workings of the free market of consumers and producers, and so pushed the freely choosing, autonomous individual to the ideological fore. This rapidly changed when the adverse results of previous privatisations of government tasks (e.g. railways, energy, welfare) became so evident that no one could deny them any longer. A similar influence on the political and public consciousness was the progressive damage to our natural environment. Everyone became aware that fighting environmental risks could not be left to moralizing the individual's private consciousness. Furthermore, partly in reaction to globalisation, more and more people openly expressed their longing for more community. As a result of these diverse developments, there came a swing back from an individualizing approach to social issues to a more collectivist one, in which the government was called upon to operate as organiser and supervisor. The previous talk about the responsible individual and his free choice now was denounced as being both sociologically naive and politically suspect – often by the same opinion leaders who had previously extolled the virtues of individual responsibility! And finally, last of all, our politicians and policy makers finally caved in to the message the obesity-experts had been sending them for almost two decades.

For a long time the dominant conception had been that the individual should be held responsible for her own successes and failures. This was also how the victims of obesity were blamed. Not surprisingly, all this moral and financial pressure forced these individuals to fight back. They did this by showing how in fact others were responsible for what at first sight seemed an individual weakness of the will. Being poised in the ideology of individual responsibility, at first the general public frowned when obese customers started to sue MacDonald's and other fast food chains. But when they booked a modest victory in 2009, more obese people started lawsuits against other culprits. Advertisers of sweets and fast food were the next to be sued. This consistently failed, because they were largely protected by the freedom of information laws. However, – following the example of tobacco advertisements – popular pressure led the government to forge a covenant with the advertisers to make clear what health-damage was wrecked by the products they promoted. For example: each bar of chocolate now carries a warning in huge letters on its wrapper, laying out all the health risks of eating too much sweets. But respondents say that they are even more put of their appetite by the complimentary photo of a very

unhappy looking obese person. After that it was the turn of the food scientists, who had first claimed that all vegetable fats were healthy, only to later prove that many vegetable fats were not healthy at all. The lawsuit failed, but the result was that there was a demand for more government intervention in the food sciences, to develop procedures to ensure that health-related information were from now on to be more thoroughly checked before being made public. After that, a student filed a lawsuit against her former school for failing to supply and stimulate healthy lunches. She argued that the school was co-responsible for her obesity because it had neglected an essential task as an educator. In the end the school was fined to pay part of this students medical bills. A final row of lawsuits was filed against employers, who were held co-responsible for the health of their employees. They were charged with the fact that they had forced their employees into a sedentary work-environment, where it was virtually impossible to acquire a healthy amount of movement per day. These lawsuits failed because the judge ruled that employees had had enough opportunities to sport in their spare time. But the labour unions took over the complaint and succeeded in effecting changes on the work floor, partly by convincing the employers that a healthy workforce was in their own interest too. So, although most lawsuits failed, they did fuel a growing apprehension that an obese person is only the end-result of what can be truly dubbed a multi-actor process. Fighting obesity therefore requires orchestrated action, which only the state can initiate and regulate.

Together the two developments paved the road for a new perception of obesity and correlating policies, which stressed the responsibilities of corporate actors for the obesity of large parts of the population. Some consequences of this new perception were:

1. Obese people from now on confidently claimed that the costs of trainings, artefacts and diets had to be paid out of public funds. Why make them pay individually for what was essentially collectively produced misfortune? Politics ceded to their demands, because obesity was finally acknowledged to be less a matter of agency than of structure.
2. The state came up with new laws to ensure that corporate actors were made co-accountable for weight-problems in the citizenry, thus motivating them to make food(supplies) healthier.
3. But more influential in the end proved to be the covenants that the government made with the corporate actors. These circumscribed their societal responsibilities and how they should operate to honour these. As a result advertisements virtually turned into health-warnings, computers began to admonish their users to take some exercise,[3] and elevators had stickers – if they were not closed right away – which read: Are you ill that you cannot walk the stairs?
4. The state initiated policies to educate lower income groups with unhealthy eating habits.

[3] A development that had been foreshadowed by the so-called anti-RSI-programs at the turn of the millennium.

It was in this general constellation that *genomics* became prominent. With the increased knowledge of the multifactorial causes of obesity, our responsibility for public health took on a new form. Genomics scientists were the first to advocate large screening programs directed at the population as a whole. People have different genetic dispositions of which they are unaware. Of course, the 'worried well' find their way to the geneticist to have their genome mapped, but this is only for the happy and educated few. Common diseases like cancer and atherosclerosis cannot be fought on such an ad hoc socio-economically biased basis. If we know everyone's genetic profile, policies can be developed specifically for particular risk-groups.

With the benefit of hindsight, one can only regret that it took so long before the new science managed to change public health policies. But in the context of those days, it was in fact quite understandable that people reacted lukewarm. Politicians were above all concerned about the soaring costs of our healthcare. They were definitely not waiting for scientists with new, costly plans. It took a lot of lobbying by the scientists to have them change their minds. First, scientists pointed out that for the foreseeable future genomics would generate hardly any new drugs. They stressed that most common afflictions were multifactorial in character, and in all probability too complex for a simple 'pill'. The policy they advocated was about prevention, about saving money instead of spending it on expensive medication. Furthermore they pointed out that the environment can only be effectively shaped on the basis of scientific knowledge about the interaction between the genes and the environment. Furthermore, the scientists argued, politicians had a professional responsibility to look at long-term consequences. Yes, they agreed, in the short run large scale screening of the population costs money. But because screening makes prevention possible, we will avoid all kinds of medical costs in the long run.

Genomics equally reinforced the well-known point that prevention of obesity was much more effective and efficient than correcting one's weight problem in a later stage. However, to be really successful, the prevention would have to start at a really early age. To reach the children, preferably from the moment they were born, meant that the government would have to intervene much more directly into the private sphere of the family. In 2012 the *Gezondheidsraad* (National Health Council) advised that everyone should be regularly tested for gene mutations, the politicians changed their positions.

One of the first experimental screening programs was directed at finding genetic dispositions for obesity. The program started relatively modest. The idea was that only patients with hereditary obesity in their families would be offered the test. However, this proved to be impracticable because without community genetics it was impossible to determine whether families were obese because of their genes or mainly because of their lifestyles. Nature and nurture are so intertwined that it is useless trying to separate the two. Environments can cause genes to mutate and genes can cause people to seek certain environments. For this reason medical professionals started to convince politicians and policy makers that everyone should be regularly screened from childhood onwards.

For a short while politicians were worried that there would be a large popular uproar that the screening programs infringed upon our privacy rights. In the

first decade of the third millennium programs like this would have been politically impossible because the discourse of individual responsibility laid much stress on the value of privacy. And indeed, there were still some elderly radicals who protested vehemently. But the majority could not care less; in the decade before, the war on terrorism had already accustomed them to the idea that privacy is not an absolute value, but may be put aside in the name of safety or health. More importantly, by this time interventionist government programs had been developed for children of ethnic minorities, whose parents spoke the national language insufficiently. The idea was that these children should not have to start their educational careers with a language handicap. This government program provided the knowledge and infrastructure for the new obesity-prevention program. It paved the way for other government measures directed at small children.

Large scale genetic screenings helped identify the groups with a particular risk to develop obesity, and community genetics then took over with a host of measures tailor made for these specific groups: information, advise, coaching, motivational trainings, etcetera. Of course, it would not do to simply check everyone's genes and then send the results at their homes. The interpretation of genetic data requires medical professionals, so they have to play a key role. By and large, the target groups were fairly open and cooperative, knowing hat they had a considerably more than average risk to become obese.

Nowadays large – medically supervised – prevention programs for obesity have become well embedded in society. Investments followed demand and shifted from pharmaceutical genomics towards nutrigenomics. This resulted in a rapid increase of knowledge regarding what nutrition is good or bad for people with this or that genome. More and more it has become clear that people from different ethnic backgrounds sometimes react quite differently to the same nutritional ingredients. What is healthy for one group can be poison to others. Restaurants began to cater for different genetic groups, their menu-cards containing information about which dishes were inadvisable for people with specified gene-mutations. However, there were also surprising discoveries made, e.g. that the people with Celtic forbearers reacted exceptionally well to Indonesian food, resulting in a whole chain of Celtic-Indonesian restaurants. The food industries were quick to adapt their marketing strategies to the new circumstances and developed different foods for different gene-groups.

An important finding of genomics was that bad food (too much salt, sugar and animal fats) modifies one's genetic make-up, with a life-long addiction as a result. This strengthened the causal link between the advertising, selling or providing of junk food on the one hand and obesity on the other. Now genomics had established this link it became virtually impossible for schools, junk food sellers, and advertisers, to deny their own responsibility for the obesity of those they had seduced. They could no longer hide behind the claim that they had not known. In this way genomics reinforced the already discernable shift from individual responsibility to corporate responsibility. New duties evolved for the likes of MacDonald, new rights evolved for the consumers.

At the start, information campaigns – now enthusiastically endorsed by most politicians – were specifically directed towards young women and mothers. Beautiful models appeared in all the media to extol the benefits which screening, followed by individualized diets, had brought them. Elderly models gravely told about their responsibility for the health of their children. And women were quick to take up the message. They volunteered on a large scale to be tested. Because women still play a strategic role in educating the next generation, children quickly followed suit. The third group to fall massively for the new obesity prevention program were the aging baby boomers, still desperately clinging to their faded youth. Young and middle-aged men were slower to react. A special campaign was designed for them, stressing that a healthy diet and MBI resulted in better energy levels, and it was suggested by the accompanying imagery that this would improve career chances.

Nowadays most people accept that obesity is largely a product of environmental factors. But some corporate actors, fast food corporations and advertisers especially, keep testing the water by trying to shove some more responsibility onto the plate of the individual.

And they are not alone. Not everyone is happy with all the progress booked. In the lower socio-economic strata there are still many men who are hard to convince of the benefits of prevention. For certain young men it even seems to have become a sign of manliness to purposely eat bad food, laughing death in the face as it were. In certain ethnic groups young women equally flaunt death by over-eating, because excessive body fat is considered sexually attractive.

There also exists a considerable minority of non-obese citizens who protest what they see as the paternalism and interventionism of the state. Genomics, according to them, shows how different people are. One can never develop general policies that are so fine-grained that they can do justice to all these individual differences. Only the individual knows what is best for her. Even if one has the genome to safely eat fast food, it has become virtually impossible to acquire it. They refuse to pay for most of the prevention-policies. More generally, they protest against the progressive medicalisation of all domains of life. According to these radicals, we have become obsessed by preserving our health, thereby neglecting all the other values that make a human life truly meaningful. Their favourite form of political protest is setting up large tables in public spaces, loading them with food, and then inviting people with all different types of genomes to join them in sharing the same food together. That this comes down to poisoning some of their guests, does not seem to worry them. . .

Although at first glance this group might have a point, their arguments hide a fundamental egoism. The simple fact that you are ‘lucky’ in genetics should serve as an incentive to help your fellows who were less lucky, instead of using this genetic luck as an argument to distance yourself from your fellows. Especially because their sacrifices are very minor compared to the benefits we all reap as a society.

More surprisingly, we also see some of the citizens who indeed have been diagnosed with a heightened risk for obesity, object to what they see as discrimination. They think it is quite unfair that they are subjected to all kinds of interventions from which others are spared. For this reason they sometimes sabotage the programs that have been devised for their own good.

Scenario 3: The Liberation of Fun

The first two decades of the new millennium witnessed a rapid progress in our knowledge of the genetic background of obesity. Although being a multifactorial affliction, for a small group of patients' behavioural changes have no use. For years they demanded a genomics based obesity drug, as it has been successfully developed for a host of other diseases in recent years. However, being a minority, they were not commercially interesting to the pharmaceutical industry. Therefore the government decided to subsidise the development of an 'orphan drug' for this group. And with this aid, genomics researchers have indeed managed to develop a drug that restores the normal functioning to these patients' bodies. Furthermore, nutrigenomics has developed some kinds of health food, e.g. possessing less saturated fats or sojabeans that are genetically modified to possess fish-oil.

Initially, the drug was only administered to obese patients after their condition has been thoroughly checked for the relevant genetic mutations. But many cures for the really ill develop into enhancements for the not so ill. As we have seen happen earlier with such now common household drugs like Prozac and Ritalin, anti-obesity medications have rapidly become popular life-style drugs, easily obtained through the Internet (for a real story about anti-obesity-pills, see Chapter 14). Why restrict your diet to health food? Why suffer and sweat in gyms, when the same result, a lean and mean body, can be obtained in a much easier way by taking a pill? This development was of course enthusiastically supported by the pharmaceutical industries. Their commercial successes have drawn extra capital, and new genomics based medicines against obesity are currently put on the market in a steady tempo. This all happened very quickly, because the weight-industry already had its whole marketing machinery in place – advertisements, distribution channels, and selling points – waiting as it were for the appearance of these obesity drugs.

The vast majority of the obesity pills nowadays are taken as a form of enhancement. Of course one cannot expect the community to pay for this use. But there is no ground to forbid consumers this use of the obesity drug either, because they harm neither themselves nor others. Individuals are therefore free to purchase on the market whatever obesity drugs they want and can afford. It is indeed unfortunate that obesity is now rapidly becoming a biological marker of belonging to a low-income group, but that is only the price to be paid for our freedom as individuals. And anyway, nothing stops poor people to control their weight in the old ways: eating less and exercising more. Both are still free!

The availability of a cure for obesity has profoundly changed our moral outlook on obesity. First, since medication is available, obesity has transformed from a sin into a disease. This transformation was avidly taken up and propagated by the obese people themselves. Understandably, because they had been suffering for ages under the moral denunciations by others. The result has been a rapid a-moralisation of obesity. Physical exercise is increasingly seen as a waste of valuable time, better spent in productive areas. Many have even gone further and now claim enthusiastically that for the first time in human history hedonism itself is liberated. At last having fun is separated from the punishment of disease. Nor is their any reason for

guilt: the individual is not burdening the collective with the costs of her medication. Finally life style has really become a matter of free choice.

Also, people started questioning previous attempts to hold corporations accountable and to remove environmental causes of obesity. Thanks to this pill, they argue, the rationale for applying the blunt, undiscriminating policy of environment-change ceases to exist. There is no longer need for state interventionism, now people can effectively control their body weight with the help of medication. The human organism, they say, is programmed to save energy. No one *likes* to climb a stairs when they can avoid it. According to them, the new medication offers us a way to obey our natural impulse to laziness, instead of being forced to do unnatural exercises.

For some conservatives, however, this liberation seems to have come too late. They stubbornly stick to the old position that having a healthy bodyweight only 'counts' when it is the result and reflection of having a strong character and inner worth. Since the obesity pill is marketed, these old style moralists have begun propagating 'natural' weight-control, because that is so much more 'authentic'. There is as much difference, according to them, between exercising and taking a pill, as between Rembrandt's *Nightwatch* and a copy of that painting on the lid of a tin box. Well, if they want to be masochists, they are of course free to choose that lifestyle. If only they would stop bothering us neo-hedonists!

From the other side of the political spectrum, the remaining parts of the 'loony left' still desperately clings to the outdated view that obesity should be indirectly dealt with by changing environmental factors. According to them we are propagating a 'technological fix' to obesity: the attempt to superficially fight the symptoms of structural deficiencies in the way we have organised our lives. They warn us that we will literally end as drug-addicts who have sold their soul to the pharmaceutical industries. One can only reply that it is they who are subject to a 'social fix': trying to solve social problems by elaborate social means. That may seem logical in theory, but is very ineffective in practice. Medical technology is often able to provide solutions that are much easier to implement because these do not demand from people to change their established routines. We have to thank genomics for developing these solutions.

Conclusion

The new opportunities and possibilities created by technology, give often rise to controversies about new rights, obligations, responsibilities, the just distribution of costs and benefits, and conceptions about the good and virtuous life (although admittedly seldom in these terms. . .). Our scenarios try to show how new technology is interpreted within existing, established moral frameworks. When a moral controversy exists, the new technology is bound to be assessed in quite diverse ways. One party tries to show how the new technology based opportunities – preventive measures against obesity for example – reinforce the discourse of individual responsibility; the other party thinks the new knowledge makes it inescapable that corporate actors finally accept their responsibility and to develop large scale screening programs. The

discourses sketched here definitively possess their own kind of robustness; they are not simply shoved aside by the new technologies. The scenarios even show that the dominant moral discourse sometimes influences the course of scientific and technological research. The second scenario provides an example of this, where R&D investments are shifted from finding an obesity cure to developing functional foods due to the dominance of the environment-discourse.

However, new technologies possess their own kind of robustness. Not all interpretations are possible. They cannot always be seamlessly integrated in the established moralities. Compare it to reading a text: different interpretations are usually possible, but not all interpretations. New technologies force moralities to adapt to new realities, and sometimes this results in serious changes of these moralities, or causes shifts in the relative strength of the different positions in a controversy. For example: an increase in our knowledge about risks is bound to result in an increased responsibility for someone, even if it is contested for whom exactly. And it is equally unavoidable that this is bound to influence established conceptions of the good life. Technologies pose new problems, and the established moralities have to come up with new solutions to these problems. That is how moralities grow and change. And the more invasive the new technology is, the larger the moral changes.

This is shown in particular in the third scenario about the obesity pill or some gene therapy: an effective and relatively cheap genomics-based drug that somehow changes our metabolism so that we can consume without acquiring extra bodyweight. Science now offers an alternative route to deal with obesity by means of medical biotechnology, and that fact alone decreases the 'necessity' or rationale of 'moralizing' and 'environment control'. The existence of an alternative route means that the arguments underpinning 'moralizing' and 'policy' are weakened. And the (moral) costs of both strategies, guilt for the one, restriction of personal freedom for the other, are brought out more sharply. Some of the proponents of these discourse will choose to adapt to the new biotechnology and modify their position, e.g. by saying goodbye to moralizing and embracing hedonism. Others will try to develop new arguments for their old position, like those who suddenly start attaching a lot of importance to the 'naturalness' or 'authenticity' of weight-management without medical help. Or those who stress that taking medication only fights the symptom, not the causes, and makes us dependent on the pharmaceutical industries. This in time of course invokes new counter-counterarguments and so on.

The previous scenarios do not pretend to foretell the future. There is only one thing sure about the future, and that is that it will take us by surprise. The goal of the scenarios is different. They aim to sensitize us to the co-evolution of technology and morality. Although we do not know how technology and morality will influence each other, we can be pretty sure that they will somehow. And when we develop new technologies, it is best to prepare ourselves for this interaction. Our current discussions about the morals of dealing with obesity can be enriched by imaginative accounts of the ways our moralities interact with technological development.

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Chapter 8
Direct-to-Consumer Genetic Testing: How the Promise of a Personalised Approach is Being Squandered

Henk van den Belt

Introduction

Genomics holds out the promise of a more personalised approach to medicine and nutrition and claims to have overcome the dangers of 'geneticisation' by attending to the subtle interplay between genetic and environmental factors. Sometimes, this promise is also considered a reason to enhance consumer (or patient) autonomy by removing medical experts from decision-making processes. In this vein several firms have set up direct-to-consumer (DTC) nutrigenetic testing services after the example of Myriad Genetics with DNA testing for mutations in breast cancer genes. However, it is an open to question whether such DTC arrangements will indeed enhance the autonomy of consumers instead of exploiting their credulity. It now appears that in their eagerness to turn the 'personalisation' promises of genomics to immediate profit, many of the companies in the nutrigenetic testing business have also largely destroyed the future credibility of these promises. In the heat of the controversy, the potentially more nuanced approach of genomics has also given way to an old-fashioned polarisation between genetic and environmentalist discourses.

Genomics' Promises of Personalised Medicine and Nutrition

One of the promises of genomics is the delivery of a personalised medicine in the future. Whereas the current regime of medicine is mainly oriented to the diagnosis and cure of ailments according to schemes that are deemed to be valid for the entire population, medicine in the future is assumed to take a more personalised approach tailored to the specific genetic makeup and particular circumstances of the patient. The emphasis is also expected to shift from cure to prevention, giving strong attention to changes in lifestyle and nutrition with major health-enhancing effects. Fotis Kafatos, Director General of the European Molecular Biology Laboratory (EMBL) in Heidelberg, Germany, is one among many who prophesy the future of medicine in

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M. Korthals (ed.), *Genomics, Obesity and the Struggle over Responsibilities*,
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the following terms: 'The medicine of today is fundamentally generic and operates in practice as diagnosis/therapy/therapy monitoring and adjustment. In the future it will be transformed into personalised medicine, based to a large extent on genetic information and knowledge about the interplay between genetic variation, environmental effects and phenotypes. The practice will be expanded to include detailed genotypic as well as phenotypic assessment, counselling and monitoring preventive lifestyle and nutrition choices [. . .]' (Kafatos, 2002, 866). Francis Collins and his colleagues of the US National Human Genome Research Institute make a prediction that is essentially similar, though more cautiously worded: 'The discovery of variants that affect risk for disease could potentially be used in individualized preventive medicine – including diet, exercise, lifestyle and pharmaceutical intervention – to maximize the likelihood of staying well' (Collins, 2003, 841).

It is also assumed that a future medicine based on genomics will largely avoid the dangers of 'geneticisation' by taking due account of the interplay between genetic and environmental factors, thus laying the old opposition between 'nature' and 'nurture' to rest at last. In the past genetics acquired a sombre connotation of biological destiny or fatalism through its focus on rare, monogenetic diseases that followed simple mendelian patterns of inheritance. Nowadays, however, it is fully recognised that common diseases and disorders, like most phenotypes, 'have a more complex origin, involving the interplay between multiple genetic factors (genes and their products) and non-genetic factors (environmental influences)' (Collins, 2003, 839). What is more, genomics provides the sophisticated techniques that are required to unravel this subtle interplay. Despite the occasional cautionary note struck by researchers overwhelmed by the difficulty of this extremely challenging task (see Elliott and Ong, 2002), confidence in the new tools still runs high.

What holds for the future of medicine also seems to hold for the future of nutrition. Indeed, nutrigenomics, 'the next wave in nutrition research' (Fogg-Johnson and Merolli, 2000), is expected to usher in the era of 'personalised nutrition' (see also Kaput and Rodriguez, 2004). The California-based Institute for the Future rather confidently predicts: 'Just as the completion of the sequencing of the human genome occurred 5 years earlier than expected, the full integration of nutrition and genomics – personalized diets and tailored food – will also arrive early' (Institute for the Future, 2003, 12). In the new understanding of nutrition, disease prevention is said to be the primary goal. As both medicine and nutrition are heading for a more 'personalised' and 'preventive' approach, the distinction between the two will also become increasingly blurred.

Some proponents of personalised medicine and nutrition are concerned that the impending revolution will be held up by the inertia of conservative and sceptical physicians and other health professionals who are insufficiently aware of the great potential of the application of genomics. The most visionary among them are prone to give a particular twist to the meaning of 'personalised' medicine by emphasising that it also entails that individuals 'take control of their own health' and decide by themselves, thus removing the need to consult medical experts. One of them is Fred Ledley, an enthusiast of the genomics revolution and founder and chairman of the company with the telling name *Mygenome.com* (see the corresponding website) (Branca, 2003). He holds that, despite widespread interest for genetic tests among

the American public, far too few physicians use the new possibilities to identify predisposition to disease or counsel patients on how to avoid risky environmental factors: 'While the medical community may develop the capacity to deliver some of these services, I believe we will also see the emergence of new mechanisms which enable individuals to decide on their own what tests would help them make decisions about health and wellness, pay for these tests themselves, and control the privacy of their own genetic information' (Ledley, 2001, 6). He even considers paying for genetic tests out of your own pocket rather then having them reimbursed as an essential element of consumer autonomy and control. In a public comment during the meeting of the SACGHS (Secretary's Advisory Committee on Genetics, Health, and Society) of October 23, 2003, Ledley declared: 'Privacy concerns are so profound that in some studies we and others have done, people say they would not do genetic testing if it's reimbursed, only if it's self-pay. We see a 2–1 preference for self-pay if it's associated with the ability to decide and have control over where that information goes and who sees it.' (Ledley, 2003).

Ledley considers the blessings that are promised by the genomics revolution as a reason for radically overhauling the current organisation of healthcare. On behalf of the autonomous consumer the medical intermediaries (the 'gatekeepers') are to be eliminated as far as possible from the entire circuit: 'Inherent barriers in the current healthcare system could inhibit the application of genomics to personal health. A radical reassessment of healthcare delivery models is necessary to ensure that the health benefits of genomics are realized by the greatest number of people in the shortest possible time. A model that empowers consumers with confidential knowledge of their own genome and the ability to make informed decisions concerning their healthcare represents the ultimate expression of a truly personalized medicine' (Ledley, 2002, 767). Apparently, we need to speed things up to reap the fruits of genomics. It goes without saying that those doctors who first want to see proof of validity and clinical utility are needlessly halting progress.

Ledley's impatient eagerness to eliminate the medical intermediaries from the circuit of decision-making threatens to obscure the fact that the rise of genomics confronts us with what should be a deliberate choice rather than a *fait accompli* imposed by commercial initiatives and technological breakthroughs. As a society we have to devise rules for the supply and demand of genetic tests and to regulate access to the information provided by them. This is a task of *institutional design* (Goodin, 1998). As the German health economists Peter Oberender and Jochen Fleischmann note, ethics and (institutional) economics must complement each other in this task to construct a viable and acceptable societal framework ('gesellschaftliche Rahmenordnung'), in which freedom of choice and responsibility are carefully balanced (Oberender and Fleischmann, 2003). To opt for an unregulated supply of genetic testing and for by-passing the medical gatekeepers is as much a choice of a particular institutional arrangement as would be the alternative proposal of binding testing facilities to quality standards and access to those facilities to medical referrals. It is remarkable that the latter arrangement is also justified by invoking the autonomy of the patient: only by providing expert medical advice and non-directive counselling, so the argument goes, will the patient decide to have

a genetic test on clear grounds and interpret its outcome correctly (Oberender and Fleischmann, 2003, 23). Thus Ledley's view that removing the medical 'gatekeepers' from the circuit would enhance the autonomy of the patient/consumer stands in need of further justification. His main line of argumentation centres on the rapid advances of genomics. In his opinion consumers must be enabled to enjoy these advances without undue delay.

Ledley's vision is not entirely prophetic. During the last few years we have already seen a score of companies in the US and Great Britain that offer genetic tests directly to the public or via low-threshold intermediaries like complementary therapists, pharmacists and dieticians. It remains to be seen, however, whether the commercial service of offering genetic testing (more or less) directly to the public really empowers patients/consumers to make informed decisions and take control of their own health.

Prelude: The Example of the BRCA Tests of Myriad Genetics

Bryn Williams-Jones reminds us in his dissertation about commercial testing on *BRCA1* and *BRCA2* mutations related to breast and ovarian cancer in Canada that the major shift in meaning in which genetic tests are defined more and more as a 'commodity' already started some years earlier. Initially, examination of genetic predispositions was confined to the domain of medical professionals in public institutions of healthcare. Physicians determined who had access to such examination and were able to act as 'gatekeepers' maintaining the relevant clinical entry criteria. 'But genetic tests are beginning to drift from this more restricted usage to a situation where anyone with the financial resources and know-how can purchase a range of tests from a variety of sources, regardless of clinically determined risk status [. . .]. Individuals and families seek testing even when medical professionals do not deem them to be at sufficient risk, or where the risk information is considered to be of little clinical benefit; people may want to use risk information for very different reasons, such as anxiety reduction, initiation of family dialogue, or other "non-clinical" uses [. . .]. The original reasons for the use of the technology have shifted' (Williams-Jones, 2002, 73).

Undoubtedly, the US genomics firm Myriad Genetics (Salt Lake City, Utah) has been an important initiator of this development. At first it was the intention of the company to market their patented *BRCA* tests without the mediation of any medical professional. It was only after severe criticism from the medical community, and also to hedge against liability suits, that Myriad stalled that plan. At the moment American women can order the test only through their doctors, but several advertising campaigns of the company (in some states also on television) aim to target directly an audience of potential customers (for a critical analysis of one such advertisement, see Hull and Prasad, 2001). Some critics hold that in the US the physician's role of gatekeeper controlling access to medical facilities is rather limited in any case: '[P]ersistent patients can usually get a doctor to order any test they want, whether or not they've had proper counselling' (Vines, 2002). Using the

slogan 'Doctor, I need to know', Myriad Genetics adroitly alludes in its marketing to the consumer's or patient's autonomy and her need to take 'informed decisions'. Knowledge, i.e. a positive or negative test outcome, is equated with power, or the ability to master and control one's own life (compare Williams-Jones, 2002, 69–70). This suggestion is starkly at odds with the many uncertainties and impotence characterising the problem of breast cancer, which even the availability of so-called 'predictive' genetic tests has hardly been able to change.

What strikes us is the tone of resignation in which many medical journals describe the possibilities and limitations of genetic testing for breast cancer. An example is the following extract derived from *Patient Care*, a Dutch information journal for the general practitioner: 'The entire process is a long and difficult road – from the first questions in the general practitioner's office until a possible investigation of DNA in the end, whether or not eventually followed by screening and perhaps large surgical operations. *The biggest problem is still that many decisions have to be based on probabilities and not on certainties*. At this time there is still hardly any convincing and unequivocal evidence for an appropriate choice of care for carriers of a BCRA mutation and women with increased risk of mamma and ovarian carcinoma. *Thus a clear advice is still very difficult.* Hopefully, new scientific research will bring us more clarity [italics mine – HvdB]' (van Os et al., 2002). It is also notable, incidentally, that despite all temporary resignation the expectation that new research will overcome the present uncertainty is still alive. However, it is a mute question whether genomics research will indeed deliver us from the predicament of uncertainty and finally grant us clarity.

As new uncertainties typically arise when knowledge grows, it seems that the challenge may rather be how to cope with unavoidable uncertainty (compare Korthals in the Chapter 15 of this volume).

Shobita Parthasarathy, who has compared genetic testing for breast cancer in the USA and the UK, qualifies Myriad's definition of empowerment in two ways: 'First [. . .] the idea that the right to demand access to genetic information is inherently empowering suggests that the client is perfectly informed and that having access to more information is automatically beneficial. In the case of BRCA testing, where the relationship between gene mutation and disease incidence is unclear, no 100% effective preventive, early detection, or treatment strategies exist, and clients often receive access through primary care physicians who have no special training in genetics; information and choice do not necessarily improve decision-making. Second, the concept of empowerment in Myriad's system is clearly oriented towards the individual.

In the UK, by contrast, the system and its notion of empowerment have societal as well as individual objectives' Parthasarathy, (2005), 31; see also (Parthasarathy, forthcoming). The UK system is characterised by a strong commitment to the goal of equal access to health care, regardless of the patient's ability to pay or her geographical location. However, access to genetic testing is guarded by health care professionals on the basis of risk assessment procedures and clinical judgement. In this respect, the patient is less 'free' to demand a specific BRCA testing service than her American counterpart [for an American review of the European BRCA

controversy that aims to draw lessons with regard to the revision of U.S. patent law and the regulation of genetic testing, see Paradise (2004)]. The sharp contrast between the USA and Great Britain (or Western Europe, for that matter) in the clinical context of BRCA testing is partly the result of a deliberate business policy. Before 1999, when Myriad Genetics achieved a monopoly in the American BRCA testing market, there were some other domestic providers like the University of Pennsylvania's Genetic Diagnostic Laboratory (GDL), OncorMed, and the Genetics and In Vitro Fertilization Institute (GIVF), each with different 'clinical philosophies' which stressed the gatekeepers role of medical specialists or the contribution of genetic counselling as an indispensable adjunct to any testing service. By using its intellectual property position to drive these competitors out of the BRCA testing business, Myriad also drove out these alternative clinical philosophies from the US landscape.

Much of the European resistance against the *BRCA1* and *BRCA2* patents of Myriad Genetics is fuelled by the particular 'business model' that the Utah company puts into practice. The opposition proceedings before the European Patent Office in Munich against Myriad's European patents initiated by the Institut Curie (and endorsed by several other agencies and organisations in Europe) in the autumn of 2001 were formally motivated on such grounds as lack of novelty, lack of inventiveness and insufficient description. Some other underlying reasons for the European opposition procedure, however, are clearly spelled out in a brochure prepared by the Institut Curie: 'Myriad's monopoly position has given rise to a market for genetics in the United States which tends to dissociate actual testing from genetic counselling and high risk patient care and follow-up. This approach goes very much against the way we view public health care, in France and in most other European countries, where clinicians work within a model which integrates biological research, clinical investigation, and patient care, taking into account the medical and psychological aspects of diagnosis as well as the clinical history of high risk patients and their families' (Institut Curie, 2001). What the French opponents of Myriad so much resented was that a purported *private* intellectual property right like a patent could actually be used as an instrument of *public* power to dictate the social organisation of health care in Europe; they were shocked by what the Australian lawyer and philosopher Peter Drahos would have called the *sovereignty effect* of such property rights (Drahos, 1996, 158). Europeans also looked askance at the direct-to-consumer advertising campaign that Myriad Genetics launched in the US in September 2002 to drum up the public's demand for the breast and ovarian cancer tests (Myriad Genetics, 2002).

On May 18, 2004, an opposition division of the European Patent Office decided to revoke the first European patent granted to Myriad Genetics in January 2001 (EP-0699754), after a public hearing of all parties to the opposition proceedings against the patent (European Patent Office, 2004). The patent was revoked on the grounds of not meeting the requirements of the European Patent Convention in view of the relevant prior art, in particular as regards inventive step (level of invention). On June 29, 2005, the European Patent Office upheld an amended version of Myriad's patent on the BRCA2 gene, which in the course of opposition proceedings

had already been severely amputated. In the end, then, the seemingly strong patent position of the American company in Europe was effectively undermined

Another major criticism of Myriad's commercial policy, not only voiced by the European opponents, is that in its promotional material the company unduly exaggerates the importance of genetic factors and downplays the influence of environmental factors in the genesis of breast and ovarian cancer. Writing on the information about breast cancer that Myriad supplies to doctors and patients, Williams-Jones remarks that 'there are normative values in the scripts which define how genetic tests are marketed and implemented': 'Myriad's online resources for patients and physicians about risk information and the probability of developing breast cancer focus primarily on the role of genetics in disease, and much less on how breast cancer can be strongly influenced by other non-genetic factors such as an unhealthy diet, low activity level, stress, psycho-social issues, or pure chance [. . .]' (Williams-Jones, 2002, 69).

In other words, and somewhat ironically in view of the promises of genomics, the 'scripts' defining how genetic tests are marketed and implemented may themselves become major vehicles of 'geneticisation' and thus reinforce genetic determinism. It seems that the old dichotomy between 'nature' and 'nurture' has not yet been overcome after all.

'Genes Direct'

Since the completion of the Human Genome project, a score of companies have become active that try to market various genetic tests directly to the public, using no or only low-threshold medical intermediaries: Sciona (originally UK; moved to Boulder, Colorado, in 2005), Great Smokies Diagnostics Laboratory/Genovations (now Genova Diagnostics), DNA Dynamics Inc, D-FWMall.com, Genelex Corp, HealthScreen America, Imagene, GeneLink Inc., One Person Genetics (reabsorbed by One Person Health)), Bioheart Inc. (all US) and Pro-DNA (Canada) (Zitner, 2002; Pearson, 2002; Williams-Jones, 2003). In recent years the number of companies active in this field has increased considerably (for a more recent list of genetic testing companies that are directly involved in nutrigenomics, see table 9 in GeneWatch, 2006a, 48–49). Not all of the tests they market are nutrigenetic tests; some DTC (direct-to-consumer) tests that are offered relate to paternity, ancestry (genealogy), pre-natal testing, disease screening or forensics. The world of medical science is highly sceptical about the scientific value (analytic and clinical validity) and even more about the pragmatic value ('clinical utility') of many of the nutrigenetic tests that are offered by these firms (Nature Genetics, 2002; Collins et al., 2003, 843; Haga et al., 2003).

Usually, those tests claim to detect gene variations in genomic profiles that can be related to common diseases like cardiovascular disease, osteoporosis, obesity, cancer, chronic fatigue syndrome and what not. In the field of nutrigenetic testing the outcome of the test is often accompanied by a so-called 'personalised' and 'customised' advice for a change in lifestyle and nutrition or the use of special

dietary supplements. (Sometimes there are co-operations with the suppliers of vitamin preparations and other supplements resulting in obvious conflicts of interest, as in the case of GeneLink cooperating with NuGenix and Garden State Nutritionals, or of Imagene with Nutrigenomics, Inc. 'It sounds like the marketing gimmick of the century', comments Gail Vines, 2002, in *New Scientist*).

All these firms exploit an existing *vacuum of regulation*. In the US, where 'only tests that are considered diagnostic devices or those that are packaged and sold as kits require premarket approval of the FDA' (Gollust et al., 2002, 1764), this vacuum was allowed to continue when the new Bush administration dismantled the Secretary's Advisory Committee on Genetic Testing (SACGT). During the later Clinton period, this committee had elaborated concrete proposals for a better oversight (SACGT, 2000). However, those proposals entailed an extension of FDA's remit, which is politically sensitive (Nature Genetics, 2002). 'The absence of a regulatory system that requires a premarket demonstration of validity [. . .] has created an environment ripe for entry into the marketplace of tests of unproven medical value that are targeted directly to consumers' (Javitt and Hudson, 2006). Despite these drawbacks, Americans seem highly receptive to such commercial initiatives: 'The US population may be particularly ripe for DTC testing because it has a do-it-yourself ethic and is accustomed to marketed medicine and paying out of pocket for healthcare services' (Wolinsky, 2005). In the United Kingdom the regulatory lacuna emerged because the supervisory agency was taken by surprise by the new developments (Vines, 2002, 44–45). The British watchdog organisation *GeneWatch* repeatedly criticised the claims made by the suppliers of 'direct-to-consumer' genetic tests and indefatigably advocated a very stringent mode of regulation. Meanwhile in April 2003 the British Human Genetics Commission issued a report with proposals for a better regulation of genetic testing (Human Genetics Commission, 2003). For GeneWatch, however, those proposals did not go far enough: 'The Human Genetic Commission's proposals are weak and ineffective. They simply hope that most genetic tests are sold through doctors and independently assessed – but they recommend no real controls to make this happen' (GeneWatch, 2003a).

The opposition of GeneWatch towards the supply of genetic tests on a commercial basis is inspired by a marked fear of 'geneticisation' and a strong preference for strategies tackling personal behaviour and/or environmental conditions to solve health problems. The following passage, appearing in a brochure under the heading 'Genetic testing does not help you change your lifestyle or your environment', may give some idea of the underlying worldview of the organisation: 'The limited research that has been done suggests that genetic tests don't help people change unhealthy behaviours (such as smoking). Nor do they help people to escape poverty or pollution! The current massive increase in obesity is not caused by an increase in genes for obesity. Tailoring treatments to your genetic make-up will not tackle the underlying problems that cause most common diseases. There is a danger that fast-food, tobacco, chemical and nuclear companies will try to blame your genes, rather than their products or pollution, for heart diseases and cancer. It is not only people with "bad genes" who need healthy lifestyles or protection from pollution'

(GeneWatch, 2003b). In this response we see again that the old opposition between 'nature' and 'nurture' is far from dead. GeneWatch unreservedly takes the side of 'nurture' (that is, environment and behaviour) and fears that testing for genes ('nature') will only be a fatal distraction on the road to improvement and reform. (More recent reports and brochures on nutrigenomics are hardly less outspoken, see GeneWatch, 2006a, b). So much for the promise of genomics to overcome this presumably outdated dichotomy! Later on I will address the question of the *motivating force* of gene tests. Let us first have a closer look at the firms offering such tests (more or less) directly to the public.

The way in which companies like Sciona and GeneLink position themselves in the market is clearly inspired by authoritative predictions about an impending revolution in medicine. Sciona is so successful in their marketing that it even got venture capital from DSM (www.dsm.com). Indeed, judging from their marketing efforts, one might be excused for believing that the predicted era of personalised medicine has already firmly come to pass. Sciona's former UK managers Gareth Roberts and Keith Grimaldi, for example, appealed to Ledley's views to justify their company's mission: 'We help achieve this aim [*viz.*, Ledley's aim to realise the health benefits of genomics for the greatest number of people in the shortest possible time, see the quoted passage above] by the simple expedient of helping people to help themselves by optimizing their nutrition' (Roberts and Grimaldi, 2003). They held that the interactions between nutrition and genetic variations, on which Sciona's recommendations were said to be based, are properly documented in the scientific literature (these claims have however been challenged in the report of the Human Genetics Commission, 2003, 18). Sciona's advantage was that it did not offer general recommendations on nutrition, but instead 'customised' advice tailored to the special genetic makeup and situation of each individual: 'We link the dietary practices of a consumer with their genetic profile to produce advice aimed at the individual (Body Benefits^{TM}), highlighting the specific things to pay attention to from the grand sweep of best nutritional practice' (Roberts and Grimaldi, 2003). Had the delivery of personalised medicine not precisely been predicted as the most important pay-off of the Human Genome Project? Well then, this promise was finally being redeemed!

The Wall Street Journal – Europe presented a happy customer (possibly from Sciona but most probably from GeneLink: the name of the firm is not mentioned): 'David Steene ordered a do-it-yourself home DNA test last year after reading about such tests on the Web. The results persuaded the 42-year-old London lawyer that he had a serious risk of getting cancer. His solution? Regular exercise and daily portions of broccoli. [. . .] Mr. Steene doesn't understand why the tests should cause a fuss and says he is eager to learn everything his genes can tell him. "I can't understand why anyone wouldn't want to know," he says. In his case, he says, that information spurred him to go on a serious high-fiber diet and lose more than 100 pounds' (Pearson, 2002).

The question, of course, is whether you need an expensive genetic test for such an advice. Isn't regular exercise and eating fresh vegetables important for everyone? As Helen Wallace of GeneWatch noted on another occasion, 'A healthy diet is important

whatever genes you have. At best, these tests are a rip-off – an expensive way to be advised to eat more vegetables. Worse, you could be misled about your health' (GeneWatch, 2002a). And elsewhere, she remarked: 'For most people, tailoring your diet to your genetic make-up is about as scientific as tailoring your diet to your star sign' (GeneWatch, 2002b).

I would like to strike a note of caution, however, before we poke too much fun at any *generic* lifestyle and nutritional advice that is offered to people with certain specific genetic predispositions for being not 'customised' and 'tailored' at all. Maybe the hullabaloo about a coming age of 'personalised' medicine and nutrition has made us expect too much. Martina Cornel, professor of community genetics at the Free University in Amsterdam, emphasises that it is people with a genetically enhanced risk who benefit most, relatively speaking, from following prevention advice, even if that advice is generic in character (Cornel, 2003a, b). Thus, it may be true that regular exercise and eating fresh vegetables are good for everybody, but this prescription will be especially good for persons with certain genetic predispositions, who will add more years to their life by complying with such advice than others with a more fortunate genetic makeup. If the commercially available genetic tests are able to pick out such persons (and that may be a big 'if'!), the advice that is given to them – even if it sounds similar to the nutritional and lifestyle recommendations for the general population – could perhaps still be defended as being 'customised' and 'tailor-made'. Or is this interpretation too charitable?

Of course, there is also a problem of *motivation*. This question is generally recognised as a key issue for the societal implementation of genomics in general and of nutrigenomics in particular. According to Francis Collins and his colleagues from the US National Human Genome Research Institute, 'research on whether the personalised genomic information that is expected to become available will actually alter health behaviours constitutes a Grand Challenge for the international scientific community in the genomic era' (Collins et al., 2003, 841 and 843). So why would people be willing to follow the nutritional and lifestyle advice given by the peddlers of nutrigenetic tests while they completely ignore the recommendations for healthy living and eating that governments have been offering for many years now? Is there perhaps such a thing as the magic of the test? Susanna Haga et al. entertain this possibility but reject it in the end: 'If all would benefit from a healthy diet, exercise, smoking cessation or prudent alcohol intake, regardless of genotype, the added value of the test is unclear *unless it can be shown to motivate compliance* in those who test positive without reducing compliance in those who test negative. Unfortunately, current data suggest little reason for optimism concerning the potential for genetic test results to motivate behavioural change [italics mine – HvdB]' (Haga et al., 2003, 348).

Sciona sees the matter differently. When the company still had its headquarters in the UK, it raised the following question on its website 'How responsive are people to nutritional and lifestyle advice?' (Sciona, n.d.; accessed November 2003). In this connection Sciona referred to the results of a survey carried out by the Food Standards Agency and the British Department of Health and Social Security: 'The interesting message from this survey is that fewer than one in seven people follow

standard nutritional advice in spite of 8 years of government campaigns and millions of pounds spent. This contrasts markedly with our own customer surveys, the vast majority of whom have confirmed that they find the personalized advice much easier to follow and indeed do stick to the recommendations we make (Sciona Customer Survey). The feedback from our customers is positive. People appreciate the specific advice, *they wish to know* how they can act to help themselves optimise their nutrition as part of their larger desire to improve their health and well-being. It is also important for people who do wish to access this information that it is available' (Sciona, n.d.; accessed November 2003).

Without doubt the customers from Sciona's survey are a quite selective and rather skewed sample. Nonetheless: why do they so neatly comply with the recommendations? Could it be because they have paid a fair amount of money for the test? Or would they truly believe that the advice has indeed been 'tailored' to their personal constitution and circumstances? Do people want to be cheated?

Configuring the Consumer

Following Williams-Jones, I noted above that genetic tests may have *scripts* defining how they are marketed and implemented that sometimes can act as vehicles of 'geneticisation'. A notion in science and technology studies that is closely related to the concept of a *script* is the idea that the designers of new technologies, while shaping material objects, simultaneously 'configure' the prospective user or consumer. According to Madeleine Akrich, 'designers [. . .] define actors with specific tastes, competences, motives, aspirations, political prejudices, and the rest, and they assume that morality, technology, science and economy will evolve in particular ways. A large part of the work of innovators is that of *inscribing* this vision of (or prediction about) the world in the technical content of the new object. I will call the end product of this work a "script" or a "scenario".' (Akrich, 1992, 208). Steve Woolgar has dubbed the first part of the designer's job 'configuring the user' (Woolgar, 1991; Grint and Woolgar, 1997, Chapter 3).

The proponents of personalised medicine and nutrition and the suppliers of direct-to-consumer genetic tests often project an idealised image of the present or future consumer who is supposed to take a profound interest in the new products and services that are or will be on offer. Thus the Institute of the Future, based in Menlo Park, California, sees 'sophisticated consumers [who] are becoming more active in gathering and utilizing information they see as important to them' as one of the major forces driving the trend towards personalised nutrition. It is interesting to note that Shobita Parthasarathy draws a quite similar message for the modern health-care 'consumer' from her analysis of BRCA testing in the USA and the UK: 'Myriad's construction of a testing system highlights an important phenomenon in modern medical care: as individuals are increasingly encouraged to take charge of their own health care as a move towards empowerment, they are often assumed to be fully informed, independent, and confident decision-makers as well' (Parthasarathy, 2005, 32). For the year 2010, the Institute for the Future projects the following

mini-scenario: 'Rather than saying, "This food is good for me because it has few calories", one might find the information-empowered consumer of 2010 arguing, "I should eat this food with B_{12} because, based on my genetic profile, my body can use B_{12} to turn off the expression of my GSA 7 gene, which causes hypercholesterolemia (excess cholesterol in the blood)".' (Institute for the Future, 2003, 13). By 2010, the Institute expects, information devices will be available in the wealthiest US households 'that will do the blood work at home to identify the genetic compositions and disease predispositions of individuals' (Institute for the Future, 2003). The sophisticated consumer is portrayed as a manager of the information thus gained who can use it on his or her own or pass it on to his or her doctor or to 'a whole range of trusted agents – including his or her nutritionist, pharmacist, health or fitness club, chiropractor, or grocery store – for further analysis and recommendations' (Institute for the Future, 2003). (Parenthetical remark: The report does not raise the tricky issue of why all these agents should be considered '*trusted* agents' at all!)

A clear example of 'configuring the consumer' can be found in the set of principles stated on Sciona's website under the heading of 'Ethical Leadership'. After reaffirming its mission to harness the power of genetics for individuals, Sciona formulates the following credo:

'Sciona believes that:

- Every adult has the right to access information relating to their own genone [*sic*].
- Every adult has the right to choose with whom they share that information.
- People are capable of interpreting fairly complex information when it relates to their own well-being.
- People recognize that scientific advance is a continual process. Nonetheless, information that already exists should be made available.
- Individuals should benefit from information derived from genome research, much of which has been publicly funded.' (Sciona, 2006a)

More or less equivalent formulations could be taken from the websites of other companies, sometimes even to the point of such similarity as to suspect plagiarism by one or the other company (compare Sciona's statement of principles with the 'Ethics Statement' on the website of One Person Health, Inc. and on the former website of (One Person Genetics Inc., n.d.). Consumers are 'configured' as sophisticated information processors capable of handling quite complex information about themselves and their own genetic make-up and presumably gifted with the natural and fundamental right to have access to such information. An added bonus of this image of the sophisticated consumer capable of dealing with complex information for the firms selling genetic tests is that it can also be used and mobilised to ward off any attempt at tight regulatory oversight. (As someone in the business said, 'There is nothing to fear but the FDA'; see Branca, 2003). Indeed, the whole rhetoric of 'empowering consumers' is uncannily reminiscent of the massive lobbying against tighter controls on dietary supplements (vitamins, minerals and herbs) which back in 1994 resulted in the passing of the Dietary Supplement and Health Education Act

(DSHEA) – after members of Congress had been bombarded by 3 million letters from their electorates (Citizens for Health, n.d.; see for a critical review Barrett, n.d., and for an extensive and searching analysis Nestle, 2002, Part Four: Deregulating Dietary Supplements). This so-called grassroots campaign, though carefully orchestrated by the manufacturers and sellers of dietary supplements, was celebrated as an act of 'self-empowerment' (Leighton, 2000). The DSHEA allows the supplement manufacturers to make 'structure/function' claims (or 'health claims' in European parlance) without FDA's pre-approval based on credible scientific evidence of safety and efficacy, thereby depriving the latter agency of the statutory authority to exercise effective oversight (Mitka, 1998). In fact, supplements had been set apart as a privileged regulatory category. The onus is on the FDA to prove that suspected supplements are unsafe and ineffective, not on the manufacturers to demonstrate that they are safe and effective. The immediate effect of the new law was an explosion of dietary supplement sales, growing from $8 billion in 1993 to over $14 billion in 1999. In the latter year, 85% of all Americans had taken a dietary supplement (Mitka, 1998). More recently, however, due to a series of highly publicised incidents and scandals, the American public has become less confident in the quality and efficacy of dietary supplements and is often confused about the health claims that they bear. Nevertheless, political and bureaucratic attempts to a give a greater regulatory role to the FDA in overseeing dietary supplements are still fiercely resisted by a motley coalition of consumer groups who even invoke their First Amendment rights to defend what they consider to be 'health freedom'. As one self-styled 'grass roots activist for health freedom', Christina Crawford, writes, 'Government regulation can give us a false sense that we're being cared for. The fact that judgements are being made for us absolves us of personal responsibility. *A better route lies in empowering people to make their own choices and challenging producers to define and meet the highest standards*. Consumers of dietary supplements are strongly motivated to buy the best quality products they can. Freedom of choice is our best guarantee of having both high quality dietary supplement products and a vigorous industry and marketplace [emphasis in the original – HvdB]' (Crawford, n.d.)

The active and sophisticated consumers, as they are 'configured' by the suppliers of direct-to-consumer genetic tests, turn out to be cut from the same cloth as the loyal consumers of dietary supplements whom the US supplement industry counts upon to serve their cause as so-called 'grass roots activists' fighting back any threat of a tightening of regulatory controls. Against this background the close alignments of several firms selling genetic tests with manufacturers and sellers of dietary supplements – see the relationships of GeneLink with NuGenix and Garden State Nutritionals, Imagene with Nutrigenomics, Inc., or One Person Genetics, Inc. with One Person Health, Inc. – are surely an ominous sign. This combination of forces – or what *New Scientist* called 'the marketing gimmick of the century' (Vines, 2002) – will possibly be successful in keeping the FDA at bay, but it also contains the seeds of many unsavoury conflicts of interest. The American genetic testing industry may be able to avoid stringent regulation in the near future, but it is highly unlikely that it will manage to escape serious liability suits for very long. After all, if necessary, sophisticated consumers will also easily find the way to the courts of law.

A Deadly Verdict

A recent report commissioned by the US Senate Special Committee on Aging and published by the Government Accountability Office (GAO) demonstrates the consequences of the absence of regulatory oversight on DTC nutrigenetic testing in the United States (Government Accountability Office, 2006). To investigate the 'legitimacy' of claims to provide 'tailor-made' nutritional and lifestyle advice to customers who send in cheek swab samples, the GAO investigation team ordered nutrigenetic tests from four companies operating through the Internet: Suracell (Montclair, NJ), Sciona (Boulder, CO), Genaissance Pharmaceuticals (Newton, MA), and Genelex Corp. (Seattle). The investigation team used samples from two persons only, an infant female and a middle-aged male, but created 14 fictitious customers to approach the companies by filling in the lifestyle questionnaires enclosed in the test kits in such a way as to suggest participation of persons of different ages, diets and lifestyles. The GAO report concluded that all the purchased tests 'mislead the consumer by making health-related predictions that are medically unproven and so ambiguous that they do not provide meaningful information to consumers' (Government Accountability Office, 2006, 5). Although the four companies have disclaimers on their websites indicating that their tests are not intended to diagnose disease, the test results in all 14 cases suggested that the fictitious customers might be at risk in developing certain conditions like type 2 diabetes, cancer, osteoporosis or heart disease. Moreover, such results are hardly informative, as any person who submits DNA 'may' be 'at increased risk' for developing heart disease. The GAO team also found that two of the four companies used the test results to recommend costly dietary supplements: 'The results from the test from Web site 1 suggested "personalized" supplements costing approximately $1,200 per year. However, after examining the list of ingredients, GAO found that they were substantially the same as typical vitamins and antioxidants that can be found in any grocery store for about $35 per year' (Government Accountability Office, 2006). The other company recommended taking pills costing over $1,800 per year to 'repair damaged DNA', although experts agree that there is currently no pill that is able to do this.

The GAO report also destroyed the illusion of 'personalised' advice. It found that the dietary and lifestyle recommendations are not based on a unique genetic profile: 'Instead, the recommendations we received simply provide generally accepted health advice directly linked to information we submitted via the questionnaires included with the tests' (Government Accountability Office, 2006, 6). The 9 fictitious consumers that had been created for three companies, based on the single sample of the infant female, all received different recommendations depending on the lifestyle information supplied. For instance, consumers who smoked were advised to stop smoking, while consumers who did not smoke were advised to continue to avoid smoking. Or consumers who ate few fruits and vegetables, received recommendations to eat more of these foods, and consumers who ate a lot of them were advised to continue to do so. 'These results lead us to conclude that we could have invented any type of lifestyle description for the DNA we submitted and the recommendations would simply echo this information. Although these

recommendations may be beneficial to consumers in that they constitute common sense health and dietary guidance, DNA analysis is not needed to generate this advice' (Government Accountability Office, 2006, 20).

The findings of the GAO study appear rather devastating to the credibility of the nutrigenetic testing industry. However, Sciona contests GAO's interpretation of the findings: 'In fact, the variation in the 14 test reports has a valid explanation. The GAO supplied genetic material from two individuals but supplied 14 different lifestyle questionnaires from 14 fictitious consumers. The service that Sciona provides is based on an analysis of lifestyle questionnaires and genetic screening together. The genetic-based recommendations remain constant, while different lifestyle questionnaires for each consumer will yield different results because of their different nutrition and lifestyle practices' (Sciona, 2006b). The point Sciona makes may be formally correct, but is not sufficient to dispel the suspicion that it is actually the dietary and lifestyle information supplied in the questionnaire, and not the person's supposedly unique genetic profile, that is the real basis for the 'personalised' recommendations. During the hearings of the US Senate Special Committee on Aging, one federal official appropriately called some of the tests 'genetic horoscopes' (Russo, 2006). Ray Rodriguez, director of the Center of Excellence in Nutritional Genomics at the University of California, Davis, defends the nutrigenetic testing industry by pointing out that the advice to stop smoking and start eating more broccoli 'won't do you any harm – and you might actually start taking your nutrition more seriously' (quoted in Kher, 2006). But as journalist Kher notes: 'The only question is whether you really want to shell out $1,000, or even $99, for that sort of advice' (Kher, 2006).

Conclusion

We have seen that firms offering genetic tests (especially nutrigenetic tests) directly to the consumer have been eager to cash in on the promise of genomics to deliver a personalised, tailor-made approach to medicine and nutrition. However, the tragedy is that in their impatience to turn this long-term promise to immediate profit these very same companies may ultimately have destroyed its credibility. Perhaps the nutrigenetic testing business may linger on in the limbo of the supplements industry, supported by its own category of 'configured' consumers who will fight off tighter governmental regulation, but chances are that it will be shunned by serious nutrigenomics researchers. Another victim of recent controversies around nutrigenetic testing is the claim of genomics to have overcome the old dichotomy between nature and nurture and adopted a more nuanced approach. Often, the scripts of genetic testing act as vehicles for 'geneticisation', while NGOs in their turn fall back on old-fashioned environmentalist discourse to articulate their critical message.

Hypothetically looking back from some possible future vantage point, we might find that the heavily advertised promises of personalised nutrition and personalised medicine have been little more than marketing hoaxes. Helen Wallace, deputy

director of GeneWatch, offers us a gloomy prospect on the likely effects of commercial genetic testing: 'Who decides what "knowledge" is in the knowledge economy? Who assesses, and takes responsibility for, the impacts of such testing on population health? Governments in both the United States and Europe seem to want to leave the answers to both questions to the market: whatever sells is valid, useful "genetic information". Inevitably, different companies will sell different interpretations of genetic risk, and different "personalized" products. This is bad for public trust, bad for investors and bad for companies who want to market valid, useful tests. Without the regulation of such tests, the human genome will, at best, become a massive marketing scam. At worst, there could be considerable harm to health' (Wallace, 2005, 517).

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Chapter 9
Genomics, Obesity and Enhancement

Maartje Schermer

Introduction

Research in genomics, at least in the popular image, holds the promise of great things to come – not only cures for diseases but perhaps also possibilities to improve and refine ourselves. The debate in bioethics on such possibilities, that have come to be known as 'enhancement', has been going on for almost a decade. Developments in genetic knowledge and techniques form an important impetus for this debate. In this contribution I intend to provide an overview of the widely diverging moral questions that the subject of enhancement can raise when related to obesity and genomics.

After a brief discussion of the different perspectives on obesity and on the meaning of the term enhancement I will present a framework to order the various moral issues at stake. I will make some assumptions about the kind of interventions that genomics research might provide us with in the future and then go on to make an inventory of the different ethical discussions that these future options for the prevention or treatment of obesity and obesity related health-problems may evoke. The intention is to offer a broad overlook of the field rather than an in-depth analysis of any one specific concern.

Health and Aesthetic Perspectives on Obesity

Nowadays, obesity is seen mainly as a health problem, and especially a public health problem. Warnings about the obesity epidemic abound. There is some discussion as to whether obesity is a disease in itself, or whether it (merely) is an important risk-factor for other diseases, such as cardio-vascular diseases, diabetes or arthritis. Some critical commentators, however, have claimed that the health-risks of being obese are grossly overstated or even non-existent (see Chapter 4 on Counter discourses, this volume.)

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Obesity and over-weight can be considered from another perspective as well, that of aesthetics or physical beauty. This aesthetic perspective on weight used to be stronger but recently appears to have been overtaken by the health-perspective, at least in public policy and perhaps also in the perception of many ordinary people. When obesity and overweight are considered from the aesthetic perspective, the remarkable different standards stand out regarding physical beauty and bodily attractiveness of (especially the female) body. Across cultures and over time, fatness has been appreciated quite differently. For example, in many less affluent societies – both past and present – a sizable posture is associated with wealth and therefore considered attractive. However, the sex symbol of the nineteen fifties, Marilyn Monroe, would be considered 'fat' by present-day standards. What is considered to be beautiful does not always align with what is considered to be healthy. Although in some communities being fat is seen as a sign of health, it can and does lead to serious health problems. And the Western female beauty-ideal tends to be so skinny, that it can become quite unhealthy. For example, supermodel Kate Moss has in 2007 a BMI of around 15 (18.5–24.9 being the normal range).

As mentioned in Chapter 3, obesity is often associated with a lack of self-discipline and the ideal nowadays appears to be 'effortless thinness'. This reminds one of the old sin of gluttony. Thinness therefore tends to be seen not (only) as healthier, but also as *morally* better than obesity. Lately, the interest in the health-care costs of obesity – estimated to be 5.7% of the national health expenditure in the United States in 1998 (Wolf and Colditz 1998) – intensifies this view of obesity as morally reprehensible. If fat people are to be blamed for their fatness, they are also responsible for the concomitant costs of their condition. In a collective health-care system these costs are partly paid for by people who are not obese themselves. In other words, or so this line of argument goes, obese people wrongfully burden non-obese people with their self-incurred healthcare costs.

Finally, in the popular image, obese people are sometimes portrayed as sociable and enjoyable people, humorists who enjoy life and are 'good company' (cf Roseanne Barr in her TV-show). However, as various sociological and psychological studies indicate obese people are generally seen by the public as less attractive, and as having more negative personality traits than non-obese people. Prejudices abound and attitudes towards the obese are over all more negative than positive. Obese people are discriminated against in the areas of employment, education and health care (Puhl and Brownell, 2001). They have less chance to obtain jobs, are likely to earn less, and are considered to be lazy, indulgent, or even 'repulsive' by a considerable percentage of nurses and medical students.

What is Enhancement?

Enhancement is a fairly recent concept in ethics, and is derived from the verb 'to enhance' which means, according to Webster's dictionary: 'to heighten, to increase, *especially*: to increase or improve in value, quality, desirability or attractiveness.' Though this broadly describes what enhancement is about, it is difficult to come

up with an exact definition of what enhancement is, let alone to determine exactly which technologies, procedures or medications fall in this category and which do not. Is losing weight a form of enhancement? It might be for someone who is overweight, but it is definitely not so for an anorexia patient. And if you are obese, does loosing weight count as a form of enhancement, or is it simply a cure for a disease? Does it matter by what means the weight-loss is brought about? Should dieting and exercise be seen as 'enhancement technologies'? Should appetite-diminishing drugs, gene-therapy, or implanted brain-chips (Health Council, 2002) be considered as such?

Enhancement is often associated with making people 'better than well' (Elliott, 2003) or going 'beyond therapy'. Enhancement is thus more than making people 'better' in the sense of curing them, or restoring them 'back to normal'. Enhancement is associated with reaching some state above or beyond the normal human condition, or with acquiring some capacities that are more-than-normal. But is the idea of being better than well applicable in the case of obesity, or more accurately, of weight? If not, using the term 'enhancement' with regard to obesity appears inappropriate. Weight typically is a trait with an optimum, not a maximum quality. More (or less) weight is not always better, there is an optimal weight for everyone – enhancement in the sense of reaching an 'even better' weight is simply impossible. Nevertheless, the term enhancement is also used for techniques and procedures that improve people in some way, even if this does not mean maximising a certain trait or capacity. Such improvements may either be improvements as compared to the average person, or as compared to the person's own natural state. Some changes that are personal enhancements are mere 'normalisations' when compared to the average of the population.

According to Juengst (1998), e*nhancement* functions as a concept in two distinct discussions: first the discussion on the proper limits of biomedicine (including discussions on the limits of medical practice, the proper role for doctors, and the funding of medical services), and second the discussion on the ethics of self-improvement. In the first context, enhancement serves as a boundary concept, marking off treatment from enhancement, or medical necessity from mere luxury. In the second context, the concept of enhancement functions more like a signpost, warning us for the various moral issues that are at stake in our quest for self-improvement. While the first discussion is clearly relevant for public policy – especially the distribution health care services – this is not directly clear for the second discussion, which focuses more on personal morality and questions about the good life. In liberal societies these have traditionally been confined to the private sphere. This does not mean, however, that people do not worry or deliberate about such moral issues, nor that a public discussion about them is impossible or absent.

If we combine the two important perspectives on obesity: the health perspective and the aesthetic perspective, with the two debates in which the concept of enhancement functions, we get a cross table of four distinct (though intertwined) moral debates. I will use this framework as a heuristic device to discuss the different moral questions that enhancement and obesity raise. Some of the moral questions clearly

Table 9.1 Relationship between health, aesthetics and two ethical discussions

	Health perspective	Aesthetic perspective
Discussion: distributive justice & limits of health care	Who should pay?	Proper role of doctors?
Discussion: personal ethics	Obligation to be healthy?	Proper means and proper ends?

belong to one of the four boxes, while others show more overlap. In some cases, it depends on one's presuppositions and one's framing of the problem, in what box a certain question is placed. As a rough division into four separate fields of debate, however, I believe the following scheme works well (Table 9.1):

In the next section of this chapter, I will discuss these four issues. First, however, lets have a brief look at the possibilities that genomics research creates to actually influence human weight and weight-related health. Can genomics 'enhance' our weight? Clearly, as set out in the previous section, it depends in part on the definition of enhancement whether any measures to influence people's body weight or related health deserve the predicate 'enhancement'. Another issue is whether genomics will enable us to influence body weight in new and unprecedented ways, or whether it will significantly change existing ways, either qualitatively or quantitatively. Genomics research will probably provide us with more insight in the human metabolism and in the (patho) genesis of obesity. It will also probably influence the way in which we understand and classify obesity, although it cannot be predicted at forehand how this will turn out (cf position paper en scenarios). One perspective on obesity that is influenced by genomics research is the idea that the stockpiling of body fat in situations of affluence is part of a 'natural' reaction of the human body, because a buffer stock of energy is very useful in times of scarcity. From an evolutionary perspective, the ability to store energy is very useful in situations in which the availability of food is uncertain and varying – as it was when humans were still hunter-gatherers. This is called the thrifty gene hypothesis (Neel, 1962). According to this hypothesis, the amassment of body fat is a potentially useful phenomenon, a way of nature to deal economically with energy. This view that obesity can be the result of a natural and under certain circumstances useful and healthy mechanism is at odds with the view of obesity as a disease, at least when using a Boorsian concept of disease (Christopher Boorse (1977) introduced one of the most influential conceptual models of health and disease: the biostatistical model). Boorsian concepts of disease rest on the idea of normal or natural bodily functions, which are disrupted in case of disease. Obesity might in this view constitute a risk factor for diseases but not a disease itself. The idea of an 'obesogenic environment' (Ravussin and Bouchard, 2000) also fits in this line of thought and opens up the possibility to see intervention directed to environmental factors that cause obesity as 'medical' or 'public health' interventions.

The term enhancement is most often used with regard to physical traits of people, although mental capacities can also be the object of enhancement (e.g. President's Council, 2003; Farah et al., 2004). The means to enhancement – at least those means

of enhancements that elicit ethical discussion – are most often bio-technological, and work through physical interventions in the body. Interventions that change the environment, or that change people through behavioural or cognitive therapy, for example, are not usually included in discussions about enhancement. Rather, these are seen as the kind of 'natural' interventions that the 'unnatural' and potentially problematic bio-technological enhancements are contrasted with. Although I do not agree with this overly simplistic view, I will follow this usage here and focus on interventions that aim at changing the body, not on those interventions directed to the environment or to personal behaviour.[1]

What exactly genomics research will render for the prevention or treatment of obesity is as yet far from clear. What is clear is that some people have a stronger disposition to become obese than others – not only because of their behaviour or social environment, but also because of genetic factors and the way their metabolism works. Perhaps it will 1 day be possible to alter this genetic predisposition, e.g. through gene therapy or pharmacogenetics and thus to prevent obesity. It may also become easier to treat already existing obesity and overweight through new types of medication. Another possibility is that the outcomes of genomics research would enable us to reduce the health-risks of being obese, for example by intervening in the process of arteriosclerosis, or by reducing diabetogenic effects of obesity. This would enable people to be fat but relatively healthy, taking away an important reason to reduce weight.

Because many ethical considerations with regard to obesity and genomics will depend on the details of the available prevention or treatment options, which are as yet unknown, I will here discuss some issues about the ethics of enhancement and obesity in a rather general sense. In doing so, I will sometimes anticipate or explore preventive or therapeutic interventions that are as yet nonexistent.

Four Issues in Enhancement and Obesity

Obesity from a Health Perspective/Distributive Justice

The two main and intertwined issues in this field of discussion are: do prevention and or reduction of obesity belong to the realm of medicine? And: who should pay for these interventions? It is often assumed that medical necessary treatments should be paid from some collective or public health funds, whereas enhancements should be paid for by the individuals who desire them. Consequently, the classification of an intervention as either therapy or enhancement becomes crucial in answering the question of who is going to pay for interventions. It thus becomes crucial to settle the

[1] Although one of the more exciting consequences of genomics research may be the possibility to influence human behavior through the body cq the genes. Developments in both behavioral genetics and neuroscience are blurring the distinction between behavior and body. (For example: Kyriacou, 2005; and numerous articles in the journal Genes, Brain and Behavior)

question of whether prevention and reduction of obesity count as medical *treatment* or as *enhancement*.

At least some means of loosing weight require medical intervention. For example: gastric banding, or the use of fat-absorption blockers like Xenical. However, using medical means is not by itself enough reason to classify an intervention as properly belonging to the medical realm, or as eligible for public funding. Plastic surgery is a good example of this. In order to classify an intervention as treatment, the goals of the intervention count too.

Interventions to reduce bodyweight often have a medical goal instead of or next to the aesthetic goal. Either the goal is a 'cure' from obesity, or it is risk-reduction – diminishing the health risks associated with obesity and severe overweight, like cardiac disease or diabetes. When obesity is understood as a disease, or as a serious risk-factor, loosing weight must be understood as a form of medical treatment and not a matter of enhancement. In that case, it does belong to the medical realm and it should be paid from the general heath-care budget.

This approach is in line with a common account to distinguish between medical treatment and enhancement, the so-called *disease based account*. The disease based account entails that all conditions diagnosed as disease by medical criteria should be treated. However, in the absence of any pathological, medical problem, interventions are considered not treatment but enhancement. This is a simple and appealing model, but unfortunately, it quickly runs into problems.

First, the question of whether obesity is a disease or not, has not been answered definitively yet, and there is no consensus in the medical community. More fundamental, there are no uniform and uncontested criteria for what should be considered a 'disease'. Different concepts of disease all have their problems and it is, moreover, likely that genomics will influence and change our concept of disease.

Second, the disease-based account also has a problem with classifying prevention. Preventive medical interventions, like vaccinations, do not offer a cure for a diagnosed disease, and should therefore perhaps be considered enhancements. But that is not in line with current common practice.

This problem also becomes obvious when obesity is not seen as a disease in itself, but as a risk-factor for getting certain diseases. On such a view, loosing weight becomes a form of prevention, just like vaccination. Or perhaps loosing weight is more aptly compared to other forms of risk-reduction, like quitting to smoke, or taking more exercise. It is not obvious that these belong in the medical realm or should be paid for by public means because, on the view that is currently dominant, there is an important voluntary behavioural aspect to these health-risks, and this implies individual responsibility. Genomics might (or might not) change this view and lead to less emphasis on the behavioural aspect and on less personal responsibility for being obese. A similar shift in focus appears to take place lately with regard to smoking, which is seen more and more as an addiction, for which one can have a genetic disposition. Since smoking has a (partly) genetic cause as well as negative health-effects, it should be medically treated, according to some (Lucieer, 2005).

Another approach to the treatment-enhancement distinction in the context of health care funding is that of *normal species functioning* combined with a commitment to *fair equality of opportunity* (Daniels, 2000; Buchanan et al., 2000). Formal equality of opportunity means that all have equal rights and effects of discrimination are corrected. Fair equality opportunity implies a 'level playing field', requiring compensation for effects of the social lottery (Rawls), as well as (in Daniels' account) for some effects of the natural lottery.

This approach turns the previous discussion on its head. Instead of establishing what counts as disease and what consequently counts as treatment, in order to determine what properly belongs to health care and should therefore be publicly funded, this approach starts on the other side. It asks what kind of medical interventions we owe, as a matter of justice, to all members of society. It explains the moral importance of providing health care to all members of society and thus offers a rationale for the (public) provision of healthcare services. Health care should be distributed fairly, meaning that it should give citizens equal opportunities by restoring or improving their abilities to the range of functional capacities typical for members of their reference class. Healthcare is thus seen as one of societies means to preserve equality of opportunity for its citizens. Although the distinction between interventions that should be provided and those that are mere 'luxury' does usually align with the treatment-enhancement distinction, this is not always the case, as we will see.

What does this imply for obesity? Does being obese impair the normal range of functioning? Yes, it does. For example: one cannot move around and do certain physical tasks as easily, it leads to a lower life expectancy, and it leads to all kinds of diseases that in turn further limit normal functioning. Does obesity lead to unequal opportunities? Yes, it does. With a shorter life-expectancy, one does not have the same opportunities to lead a full human life; the physical impairments of being obese as well as the impairments of the associated diseases and social prejudices lead to less opportunity. Those individuals who are so fat that they cannot move around anymore and are confined to their house or even their bed provide the most extreme example of this.[2] On this account, obesity should be treated in order to restore the obese citizen back to a normal range of functioning and opportunity.

However, this account overlooks one important aspect of the problem: the question of how the citizen became obese in the first place. If everyone starts out with a normal body weight and a normal opportunity to acquire food and to exercise, but some eat too much, move too little and become fat, why would this be unjust? Why would society have to make up for the consequences of these individual choices in life-style?

When obesity is considered to be a 'freely chosen' condition, it provides a clear case in which the treatment-enhancement distinction does not help to decide

[2]Of course, not all cases of obesity are that extreme and the degree varies to which normal functioning or normal opportunity is limited by obesity. In the following, I will assume that obligations to provide healthcare depend upon the degree to which opportunity is impaired.

whether an intervention should be publicly funded. Although obesity may be a disease, and there may be a treatment for obesity, society is not obliged to provide it if the condition is self-inflicted.

The situation would change if genomics would show that some people have a very strong disposition to become obese (perhaps through a combination of slow metabolism, inborn character-traits like impulsiveness or weak self-control and a high set-point for bodyweight-regulation established through a faulty diet in early infancy) and this disposition would itself be considered a disability or a disease. It would limit one's opportunities to be so afflicted, for example because one would need to adopt a special eating and exercising-pattern. The relative importance or seriousness of such a limitation would of course be a matter of discussion, but it might support a claim to medical treatment of either the genetic disposition, or the resulting obesity. Alternatively, such a predisposition could be considered 'normal', but at the low end of the range of normal functioning. If it presented the same disadvantages as a 'real' disease leading to obesity (for example a hormonal misbalance) it could be a matter of fair opportunity to 'enhance' people with this genetic disposition. (cf Brock, 1998) This would be an example of a case where the treatment-enhancement distinction does not map onto the boundary between medical interventions that should be publicly funded and those that should not.

As a third possibility, such a disposition to become obese could also be considered as a mere variation in normal functioning and in normal skills and talents, in which case it would not support a claim for publicly funded treatment. After all, according to the fair equality of opportunity account, individual traits lying within the normal range of human functioning do not need to be equalized. This account does not require a levelling of all individual differences or a redistribution of all skills and talents. From this perspective, a medical intervention to alter a disposition to become obese would be considered an enhancement and not a treatment. It would enable one to live more easily (less need for exercise and dieting) than others with the same genetic make up who were not enhanced, but it would not be considered a matter of justice to provide people with this enhancement.

Obesity from an Aesthetic Perspective/Distributive Justice

When we see obesity and overweight as aesthetic issues, rather than as health-problems, the questions concerning the treatment-enhancement distinction change. The main question here is: does weight reduction for aesthetic reasons belong to the medical realm, is it a task for doctors? The question of whether or not weight reduction for aesthetic reasons should be publicly funded is a minor question here because – as is obvious from the previous section – it is disease or abnormal functioning that entitle one to publicly funded interventions, not aesthetic considerations.

When no significant health issues are at stake, and weight loss is desired primarily for aesthetic reasons[3] (think: overweight, rather than obesity) what role should the doctor play? Does it belong to his profession to help people to look nicer? Or should he only treat diseases and cure illnesses and refrain from enhancing or improving people? Such questions are familiar from the debate about aesthetic surgery. An important difference is that weight loss can be acquired through various means, both medical and non-medical, whereas aesthetic surgery always requires substantial medical intervention. Several considerations are relevant here.

First, of course, the risks involved. Whereas there are little or no risks attached to life-style advises, such as dietary rules or exercise programs, pharmaceutical interventions will probably have side-effects and risks attached to them. Whereas a professional balancing of risks and benefits in case of health-threatening obesity may end up favourably, it may turn out unfavourable if not health but only looks are involved.

A related question is whether the balancing of risks and benefits is and should be a merely professional one. Should not the patient (or in this case perhaps better: the client) be allowed to make his or her own deliberations? In general, patients are allowed to refuse medical interventions if they do not agree with the doctor's assessment of risks and benefits, but they cannot demand interventions that the doctor considers unprofessional. Especially in the case of enhancements, this means that doctors do not have to do everything their patients desire; and that sometimes it would even be unprofessional to do so.

A second important question is what the proper task or role of medicine is. Some say it is to treat diseases, others say it is to maintain or restore normal functioning; still others claim that it is to relieve suffering. On the first account, helping people lose weight for aesthetic reasons is not a task of doctors; on the last account it might be, if the person in question suffered a lot from her overweight. However, in that case, one would not be inclined to call the intervention a form of 'enhancement'; rather it would be considered a form of treatment, just like correction of protruding ears is. In discussing the proper role of medicine and of doctors, the treatment-enhancement distinction is not proving very helpful. Rather, it appears to be a reformulation of the question.

Finally, even if we could settle the dispute over the proper tasks of medicine, would that imply that doctors are never allowed to use their knowledge and skills for reasons outside this medical domain? Liposuction for moderately oversized thighs would probably not fall within any definition of the 'proper tasks of medicine' but does that mean that doctors may not offer it to people, as they now do in all kinds of beauty-centres and private clinics? I believe that apart from safety considerations there is little reason to prohibit this. Perhaps, though, we should admit that such

[3] In practice these reasons – health related and aesthetic – will of course not always be separated. Loosing weight often has both aesthetic as well as health-related advantages and will often be pursued for both ends. Moreover, even if the patient only worries about looks, the doctor may still feel treatment is desirable because of the patient's health. However, the discussion about the health hazard of overweight and even obesity is not yet completely settled (see Chapter 4 of Van de Belt).

practices have little to do with traditional medicine and are better understood as ‘schmedicine’ (Parens, 1998). Whereas doctors might feel morally obliged to stick to their core-business, ‘schmocters’ would have no such limitations; they would simply be entrepreneurs offering services based on biomedical knowledge and skills to consumers on a free market. Whatever the possibilities that genomics research is going to provide to keep one’s body in shape, they will probably all be used by these schmocters and their beauty-seeking clients.

With the idea of schmocters as a new form of medical entrepreneurship, we have drifted a long way from the question of who should pay for the medical costs of weight loss for aesthetic reasons. In as far as reasons are purely cosmetic, collective funding seems out of the question. It would be labelled as an enhancement, in the sense of ‘mere luxury’, as opposed to medically necessary treatment. One way to avoid this conclusion would run via an appeal to psychological distress and suffering caused by the overweight. Just like some other cosmetic interventions are paid if they will alleviate suffering (the protruding ears), so an overweight person may claim a right to liposuction, or an anti-fat pill, because he is suffering from his looks and experiences psychological distress because of them. Another way would be to appeal to the social disadvantages and unequal opportunities that being (severely) overweight brings with it, like decreased chances on the job-market. These appeals would not stand much chance if the prevailing opinion would still be that overweight is one’s own fault and can best be remedied through diet and exercise. However, if overweight would come to be seen more as a matter of bad luck, for example by the discovery of a genetic dysfunction causing overweight, this would make a claim on some form of collectively funded treatment, even for cosmetic, psychological and social reasons, a lot stronger.

Obesity from an Aesthetic Perspective/Personal Ethics

Since in our society being fat is often equated with being ugly, one way to enhance physical appearance is to lose weight. The billion-dollar industry surrounding body-shape techniques and weight-loss products shows how many people (especially women) are fighting with their own bodies to enhance their looks and improve their health. Any ‘easy fix’ that genomics research might render for overweight would probably be welcomed. The moral discussions this provokes mainly concern ‘personal ethics’: questions about the good life, about virtues and about authenticity and freedom of choice. New genomics-based possibilities for preventing or treating overweight and obesity, and shifts in the way these conditions are perceived will also have repercussions for these moral discussions.

A first concern in this field of discussion is that enhancing oneself through medication or technology is, indeed, an ‘easy fix’, and not as good or as worthy of respect as enhancement brought about by one’s own efforts. With regard to bodyweight, our attitudes on this point seem to be very ambivalent. On the one hand, obesity is associated with gluttony, sloth, and lack of will power. Losing weight is therefore not only perceived as a practical matter, but also a moral one. It is a way to practice

and show off the virtues of self-discipline, moderation, determination and diligence. Losing weight should be done through effort and hard work: physical exercise and fierce self-restraint with regard to food. From this perspective, losing weight is a form of self-improvement through effort and virtue, and bypassing this route with the help of a pill or technology is felt to be morally inferior.

On the other hand, however, the success of feeding substitutes, herbal extracts and other devices that promise instant thinness shows that we do not really feel this moral pull so strongly. We do not massively blame people for using these 'easy fixes'. Perhaps, however, this is partly due to the fact that present pills and feeding substitutes merely promise but not really provide an easy fix. It does take effort, self-restraint and will-power to continue most of the diets, food-substitute programmes and other slimming technologies. But what would happen with our moral appraisal if a really effective easy fix would be available; if one could eat too much and too fat and not exercise at all and still remain thin through a pill?

Another issue that is often raised concerning enhancement of physical appearance is that of voluntariness versus social pressure. It has often been remarked that beauty ideals can be oppressive and can lead to social exclusion of those who do not live up to them. Social pressure to use available techniques to enhance oneself and adapt one's appearance to socially accepted norms might undermine the free choice of the person in question. This issue has been discussed extensively with regard to cosmetic operations and breast augmentations for women. A convincing argument has been made that although women are influenced by beauty-ideals this does not necessarily diminish their free or autonomous choice to use cosmetic surgery (Wijsbek, 2000).

At present, social pressure to lose weight is usually not considered to be so serious as to compromise the free choice of people who decide to lose weight, though some more militant supporters of the obesity movement might argue that it does and that their choice to be fat and beautiful is not respected by society. Indeed, when more options would become available to stay thin or lose weight easily, the more 'abnormal' a fat figure would become. Social pressure to use all available means would then probably increase.

A special feature of overweight that makes the issue of voluntariness somewhat less problematic than in the case of cosmetic surgery, is that (severe) overweight has negative health effects next to cosmetic disadvantages. Wanting to lose weight is not merely a matter of beauty and ever-changing fashion, but also a more objective matter of health. This means that fat people have some reason to want to lose weight, apart from any fashion norms or related social pressure.

Imagine, however, that the outcomes of genomics research would somehow make it possible to reduce the detrimental health effects of obesity so that one could be both fat *and* healthy. In that case, the health argument for losing weight would disappear, and the aesthetic argument would be the only one left. This would most likely shift the discussion on free choice and social pressure. Either being fat would not be considered to be so bad anymore, since it would no longer cause serious health-risks, or it would still be considered as deviant and un-aesthetic, despite it not being a health risk anymore. In the first event, social pressure to lose weight

would diminish; in the second case, social pressure would remain high but would be more problematic than before, since it would rest only on social and aesthetic norms.

On the other end of the weight-spectrum, social pressure is also often claimed to be a problem. It claimed that beauty norms and social pressure influence young girls' eating and dieting behaviour unfavourably, and affect the prevalence of anorexia nervosa. Apart from the question of whether this claim is justified, it is not clear that it is the social pressure itself that is most problematic here. Young girls' decisions to have tattoos or to 'pierce' various body-parts are probably made under the same kind of social pressure, but this is not seen as very morally problematic. Rather, the question is whether the norm of thinness is not a 'suspect norm', based on discrimination or prejudices and with detrimental effects.

Norms of appearance are morally suspect, according to Margaret Little, 'when their content reflects, flows from, and reinforces a system of beliefs, attitudes, and practices that together involve deep injustice' (Little, 1998, 167). She gives the examples of racial prejudice (the norm that a whither skin is better than a darker one) and gender stereotypes (a *good* woman is a *good-looking* woman). Is thinness, in this sense, a suspect norm? Does the norm of slenderness reflects or flows from a system of injustice towards fat people? Does it reinforce such an unjust system? I believe that this depends partly on the degree to which health, aesthetics, and prejudices are involved here and partly on the degree to which fat people can be held responsible for being fat.

In as far as obesity poses serious health risks and people generally want to be healthy, there is nothing inherently unjust in having a social norm that favours thinness. In as far as the norm of thinness is based on aesthetic reasons it also need not be unjust – norms of physical beauty and attractiveness always favour some people over others, but as Little remarks, this is not unjust but merely unfortunate for the less endowed. Aesthetic or beauty norms, however, tend to be different and often stricter for women than for men and in that sense can be unjust. Women are judged more on their looks than men are, and the norm of thinness reflects this.

Apart from gender-bias in the norm of thinness, it is in any case clearly unjust to discriminate against fat people in the workplace, at school or in other social institutions where a person's weight and appearance are irrelevant for his performance or functioning. The health and beauty-based norm of a slender appearance then oversteps its proper limits and becomes a discriminating norm. Prejudices and discrimination would probably become more obvious if a means were discovered to avert the health-risks of obesity and so to be both fat *and* healthy.[4] Without health as a reason to support it, the norm of thinness would lose much of its underpinning.

Perhaps the most 'suspect' aspect of the norm of thinness is that it incorporates ideas about behaviour and character of obese or overweight people. As mentioned before, obesity is associated with notions of guilt, sin, and weakness of will.

[4]Perhaps without health-reasons to uphold the norm of thinness, the aesthetic norm would also change, and 'fat and healthy' would become the new norm.

Moreover, people are often considered responsible for their obesity or overweight, while in fact they often have less control over their own weight than others think. This makes obese people more vulnerable to discrimination: the fat person who has a genetically determined metabolic problem often suffers from the same negative social attitudes as the one who is fat because he knowingly and willingly maintains an unhealthy lifestyle. Judgements of appearance thus tend to become judgements of behaviour and character at the same time. I believe this aspect of the norm of thinness is indeed suspect, but it is very difficult to disentangle it from the aspects of health and aesthetics.

When a norm is 'suspect', techniques and measures to help people to conform to this norm can be accused of being complicit with the unjust system, and of exacerbating prejudice and discrimination. By bleaching one's dark skin in order to look whither, for example, one acts as an accomplice to a system that discriminates dark-skinned people. Once again, as long as health is clearly involved, measures against obesity and overweight cannot easily be accused of being complicit with an unjust and discriminatory system.[5] We should be careful, however, that the justification of the norm of thinness in terms of health does not overstep its limits. By treating even slight overweight the same as obesity, despite the fact that overweight poses no or only limited health risks, the mainly cosmetic problem of overweight is turned into a medical problem. Moreover, new (genomics-based) options to reduce weight could be accused of complicity if they were marketed as means to improve appearance in people – most likely women – with normal weight or slight overweight, with an appeal to gender-biased beauty norms.

Obesity from a Health Perspective/Personal Ethics

When obesity is considered from the perspective of personal ethics and health, the question of enhancement can be rephrased as follows: is there a moral obligation to enhance our own health; and if so, how much effort is required and which means are appropriate? Here, issues of responsibility for health and the value of health relative to other values are important.

In liberal societies, people are entitled to live according to their own views of the good life, and this implies that people can live according to diverging value patterns. Health is often seen as a basic value, because it is a precondition to realize most other values or aims in life. Bad health usually decreases one's life expectancy and also one's quality of life and whatever one's view of the good life, these are prima facie bad things. It can therefore be expected that people, as a mater of prudence, look after their health. However, this does not imply that health is always more important than other things, or that one should always do everything in one's power to stay healthy. Rather, one will always have to balance the value of health, and the effort it

[5] Some measures might exacerbate discrimination and prejudice against obese people. For example, information campaigns that only stress individual behavior as the cause of obesity could strengthen the idea that obese people are 'weak' or 'bad'. This is something we should beware of.

costs to maintain or regain health, against other values and aims in life. For example, a nurse tending on influenza-patients puts her own health at risk, but does so because it is her task and her responsibility. The aim of looking after the sick and doing a good job is more important than preventing every possible risk to her own health. A gourmand may well find the pleasures of eating more important than the health risks of being over-weight. And anybody with a sedentary job and a busy working-schedule might find his career, his family or his rare spare time more important than spending hours in the gym to do healthy exercises.

Taking care of one's health is more a matter of prudence and lifestyle than of morality; a matter of personal choice, rather than a public duty. It can be reframed as a matter of public morality, however, when other people are made to pay for one's carelessness regarding one's health, as can be the case in collectively funded healthcare systems. This brings us back to the issues of distributive justice discussed earlier. Moreover, a condition like obesity can become a public problem if it exists on such a massive scale that social interactions and relationships are disrupted. In the United States, almost 30% of obese people (Critser, 2003) hardly leave their homes anymore because of their obesity.

A very important question is how much we are willing to do to enhance our health; how much value do we attach to it as compared to other things, and how much effort do we want to invest in it? With regard to obesity and overweight it has been remarked that the 'war on obesity' and the extreme emphasis on the health-aspects of food and drink repress attention to other aspects of eating (Korthals, 2004). For example, the social dimension of eating and drinking may become neglected when food is merely seen as potentially fattening – it is not much fun going out to diner with someone who is on a bread-and-lettuce diet. Another example is that specific eating cultures of various countries or ethnic groups may be suppressed for reasons of health – the Mediterranean cuisine is said to be healthy, but traditional Dutch cuisine should be banned from our tables (too much fat meat and gravy). Moreover, production norms intended to reduce health risks can lead to prohibition of certain products, such as certain farm-made cheeses. Health risks are then deemed more important than the pleasure of eating well. For some gourmands 'enhancing' health by deleting all kinds of exquisite food and drink from the menu would in the end result in a diminished instead of an enhanced quality of life.

For most fat or overweight people however their weight has probably little to do with conscious choices, based on a balancing of values. They do not risk their health because they find eating so much more important than health, or because they consciously choose a life plan requiring little exercise, but because they cannot resist the temptation, because the lack knowledge about healthy food, because they have a slow metabolism, or because of a number of other possible reasons. So, while the social and cultural risks of over-emphasising health risks of food and of medicalizing eating and drinking behaviour should certainly be addressed, they should be evaluated in relation to the serious problems that obesity brings about.

Finally, I want to point out one more issue related to personal views on the good life, responsibility and health: the concern for children. Making health- and lifestyle-related decisions for our selves is one thing, but what about our children?

Making lifestyle decisions that affect their health is quite something else. Parents are responsible (a typical form of role-responsibility) for their children, a responsibility that obviously includes the children's health. A healthy diet and healthy exercise habits are learned in childhood and obesity acquired at a young age has serious health consequences later in life. While passing on one's value patterns to one's children is an important part of the upbringing, and parents are to a large extent free to raise their children according to the value patterns that they prefer, parents are not free to make choices for their children that seriously harm them or significantly impair their options in life. This goes for choices that lead to obesity in children, but also for possible enhancements in children (Agar, 2004). If medication became available to prevent or easily cure obesity, this might place parents for difficult dilemmas. Why deny your child snacks and sweets if there is medication to help him keep a proper weight? But on the other hand: why expose your child to possible side effects if you could also teach him a healthy lifestyle? Even harder questions are raised by possibilities for prenatal genetic testing or pre-implantation genetic screening. If these techniques could identify embryos or foetuses with a high risk of becoming obese, how should parents, physicians and policymakers deal with that? Is preventing obesity in this way an acceptable way to enhance (the health of) our offspring?

One Step Further: Eugenics?

Before I come to conclusions, I would like to make some speculations and raise some questions regarding enhancement, genomics and obesity that are more futuristic than the previous reflections. Up till this point, I have tacitly assumed that whatever intervention would become available to prevent or cure obesity it would be used on an individual basis. However, some already speculate on more profound changes we might 1 day be able to make in our genome and thus in large groups of people, perhaps even our whole species. Suppose we could change our genome in such a way that we would be less prone to obesity, would this count as an enhancement? And would it be morally acceptable – or even morally required?

If we accept the 'thrifty genotype hypothesis', which states that through evolution we have developed survival mechanisms against periods of food scarcity, it could be argued that a natural trait that is useful under some circumstances has now 'turned against us' and is causing obesity. Our genes have stayed the same, but our environment has changed from scarcity to affluence.[6] Ravussin claims that obesity has in our present environment become an 'essential condition', and states that 'what was an asset in early mankind history has now rapidly become a liability' (Ravussin and Bouchard, 2000, 135)

From this perspective, it would be an enhancement if we would change our natural predisposition for economic energy-use to a more lavish use of energy. We would

[6] 'Us' refers here to people living in affluent societies or circumstances. It is an acrid fact that while one part of the world population is dying of too much food, the rest is still dying of too little.

be able to eat as much (or more) than we do now, and move just as little, without becoming fat. We would not have to change our lifestyle to maintain a healthy body, but we would change our bodies to fit our lifestyle. Since this could be viewed as a way to adapt ourselves better to our present needs and environment it could be understood as a form of self-evolution (Fuchs-Simonstein, 2004).

Apart from safety concerns – which would probably be massive – would this be a morally problematic form of enhancement? Would this somehow make us less human, or post-human; and if so, would that be a bad thing? Would such enhancements be purchased on an individual basis and would they perhaps only be affordable for the wealthy upper-class? Or would they be provided and promoted as a public health measure to be used by all?

On a more fundamental level: is it wrong to 'play God' like this, or to aim to change what nature has made us? There will certainly be people who will claim that it is. But why would we not adapt ourselves to new circumstances and aid our own evolution a bit? Is it morally better to control and alter our circumstances, rather than adapt our bodies? And from a quite different perspective: would changing our genome to make us fat-resistant be a fair thing to do in global perspective – would it be just towards all those people who have too little to eat, instead of too much?

These will be left open questions here, intended to show that there is much ethical discussion about enhancement beyond the questions I already raised. It is, however, not likely that we will have the option of designing and altering our genome at will available to us in the near future.

Summary and Conclusions

I have discussed some of the ethical issues related to obesity and human enhancement using a rough division into four problem-fields. It is clear, however, that this subdivision is not absolute and that there are connections and correspondences between the various discussions.

Many of the questions discussed above are situated on the intersection of public and private morality. While people should be allowed to make their own choices and live (and eat) according to their own value patterns, it is clear that both eating behaviour and body weight are not strictly private matters but issues of public concern as well. They are so most obviously because of public health concerns and the issue of fair distribution of healthcare costs, but also because of the cultural and social effects of an obesity-epidemic. These other-regarding effects of individual lifestyles place weight, eating and exercising issues on the borderline between private and public morality.

For many ethical issues, the demarcation between the health and the aesthetic perspective is important, but it is also clear that this is a contested and not always clear division. Health and aesthetic considerations do sometimes overlap or coincide, but can also diverge. Moreover, the developments in genomics may change the health

and aesthetic perspectives, as well as their mutual relationship. The powers that genomics research will give us to intervene in the human body as well as the changes it will bring about in (public) perception and attitude towards obesity and overweight, are not easily predicted and might go in many directions. Nevertheless, the ethical discussions that efforts to enhance people's weight and weight-related health will evoke, will probably fall somewhere in the framework that I have sketched. Which of these ethical issues will prove most pertinent and what exactly the outcomes of the discussion will be, will depend on the further developments in both genomics and society.

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Part IV
Cultural Framing of Genomics-Obesity in The Netherlands and Italy

Chapter 10
Obesity and Genomics in the Netherlands

Michiel Korthals

Introduction

In this chapter the Dutch debate on the main causes of obesity is described and reviewed as well as the current initiatives adopted by the Governament and private initiatives to tackle the problem. The first part gives an overview of the Dutch situation. The second part of the chapter reports on expert opinions on the possibility to address the problem of obesity through different approaches. Several Dutch experts and practitioners are invited to express their views on the problem of rising rate of obesity in the Dutch context and their opinion on the possible ways to tackling it through cure, prevention, and regulation. The three constellations of responsibilities and causes, as described in the previous chapters in this book, have been used to prompt a debate with about the genomics approach to obesity by a group of Dutch experts, addressing more specifically the possibilities and problems.

Overview of the Dutch Situation

Just like other European countries, the Netherlands show rising numbers of overweight and obese people. Approximately in 1990 one in three Dutch inhabitants is overweight and one in ten is obese. For 2008 the numbers are: 40% of the men and 30% of the women are having overweight and 10% of the men and 12% of the women are obese (CBS 2008, p. 113). As everywhere, overweight and obese people are not equally spread over the population. In the developed world and contrary to the developing world, lower income groups are overrepresented, but also people that live only one or two generations in the Netherlands. In the Netherlands of the 2–21 year old children 13% of the boys and 14% of the girls have overweight (Fredriks et al., 2000; figures from www.cbs.nl)). In the big cities and in places with children from non-Dutch parents the overweight rate is even higher (De Wilde et al., 2003). In particular under girls from Turkish parents a strong trend to overweight is

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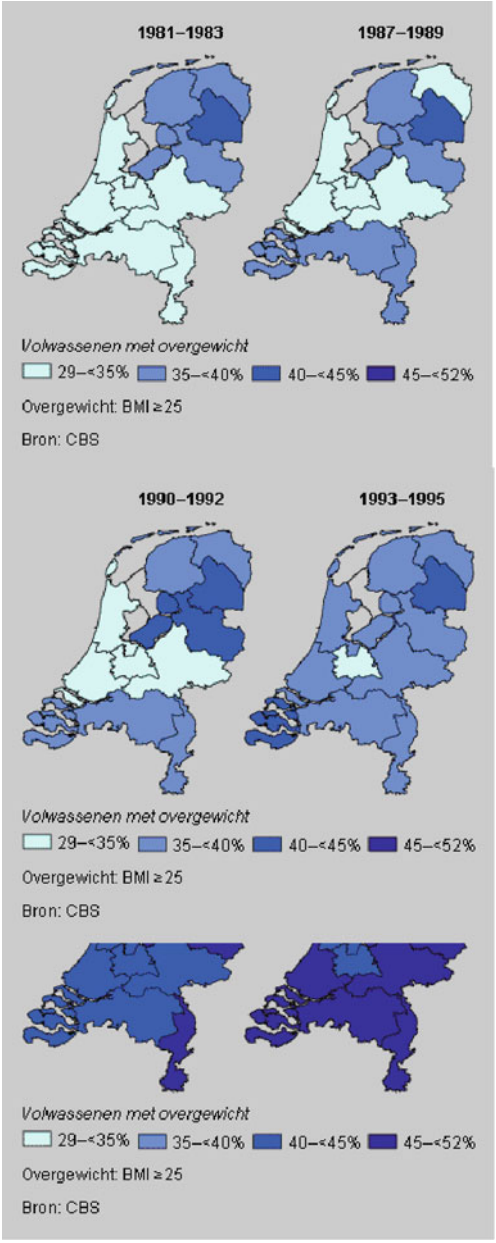
visible: more than half of Turkish girls have overweight; obesity is also higher than in other population groups. The total costs of obesity are estimated for direct cost (with respect to medical care) on 500 million E and for indirect costs (economical costs) 2 billion E. Overall, according to the RIVM, will the number of obese people increase in the Netherlands in 2024 by 18% to 2.5 million. 9% of the population will have diabetes 2.



However, it is not that in the Netherlands a non-obese life style is difficult to keep up with compared with for example the United States, with an obesity rate of one in third (32% male and 37% female (WHO)). With respect to consumption of food, fruit and vegetables are rather easy to get and they are not more expensive than calorie rich food. Moreover, there is a long standing habit of going by bike to work or school (although that is changing) which means that people are encouraged to perform exercises daily (see for more information on the USA, Stearns, 2002).

These habits can be easily connected with the way food and health is seen by Dutch consumers; it is illuminating to refer to several comparative studies on this issue. The most fundamental idea of those studies is that food choices are part of a food- and lifestyle and express and explicate the identity of the person making that choice. The different food- and lifestyles comprise different conceptions of food and health Payer, (1998); Grünert ,(1997). In general, we can distinguish different ways of relating to food, such as the dichotomy expressed in whether one eats to live or lives to eat (Stearns, 2002). Food choices are generally based on attraction or disgust of which Rozin and Fallon (1987) state: 'Disgust is triggered not primarily by the sensory properties of an object, but by ideational concerns about what it is, or where it has been. In fact, we conceptualize disgust as a distinct form of food rejection, different from rejections based on bad taste or on fear of harm to the body.'

In the Netherlands, just like other countries, one can discern a multiplicity of food- and lifestyles that represent multiple – sometimes unconventional – forms of mutual solidarity and socialization. Sociologists such as Giddens (1991), Beck (1990) and Schulze (1992) identify this as typically for Western people living in a late or postmodern society in which individualization is the main structural trend. Food- and lifestyles are in a state of flux, to a significant degree due to technological and scientific developments, such as food innovations, computer technology, modern means of communication, or new means of transport. It is quite surprising that these studies all agree upon a similar general frame of four or five foodstyles and they are also characteristic for the Netherlands, although the proportions are different compared with for example France and Italy.

Rozin et al. (1999) have done extensive research on the different conceptions that people in different cultures have with respect to food and health. They conclude that 'generally, the group associating food most with health and least with pleasure is the Americans, and the group most food–pleasure-oriented and least food–health-oriented is the French.' Rozin et al. (1999) emphasize that the pleasure orientation towards food and the minor role of health considerations is probably an important factor in the explanation of the French paradox, i.e., the fact that overweight and obesity is less prevalent in France although fat intake is as large as in the US. 'One account of the French–American contemporary differences has to do with different traditional eating patterns in the two countries, with a French emphasis on moderation and high quality, and an American emphasis on high quantity.' The Dutch consumers are to be placed somewhere in the middle; the Italians agree with the French.

On the basis of a structural theoretical background Douglas (1982) has analysed empirically four broad types of food styles or food cultures. She distinguishes a traditional (hierarchical) food culture, where food is seen as unspoilt nature (regional,

authentic cuisine); an exclusive food (individualist) culture, where food counts as an exclusive identity item (high culture); an information and fast food (egalitarian) culture, where food is viewed as fuel; and an eclectic (individualist) food culture, where food is seen as part of an enlarged global conversation of a plurality of cuisines (slow food). These cultures or styles are confirmed by the work of the Dutch marketing and research company Motivaction (www.cbs.nl, www.motivaction.com). Motivaction developed a research instrument to disclose value orientation of Dutch consumers and concludes on the basis of longitudinal studies since 1997 that four styles in more or less equal proportion are dominant: the traditional, egalitarian, self-realization and responsible life style. Only for the egalitarian food style is health a dominant issue in choosing food items. This means also that strategies from the side of government or industry to eat healthy will only be successful with these categories of consumers.

It is striking that all the elements of the three constellations, behaviour, environment and body, are present in the Dutch governance of obesity, with emphasis on the first two. Genomics applications are not used on a large scale, but see below for experts views on the relationship between genomics and obesity. The current genomics innovation strategy in the Netherlands favours only certain social institutions and values (concepts) vis-à-vis the ones that are available, as is shown in the table. For other institutions and food- and life styles this strategy is not attractive (Table 10.1).

Table 10.1 The current Dutch nutrigenomics innovation strategy and its implications for existing concepts of consumers, food styles, responsibilities and obesity discourses

Genomics concepts and applications and their attraction for existing concepts and values	Framing of consumer (food style) (Chapters 8 and 10)	Framing of responsibility (Chapter 6)	Discourse (Chapter 3)
Concept of health	Egalitarian	Individual responsibility; second one: industry	Behaviour; body
Concept of food	Egalitarian	Idem	idem
Application: testing	Active, gene driven	Market; second one: government	idem
Application: biomarkers	Idem	idem	idem
Application: products	Passive	Retail; second one: government	Environment

Role of Stakeholders

Government

The Dutch government took the decision not to regulate the problem itself but asked a self-regulatory body, consisting of the most important stakeholders, to organize the measures against obesity. Interesting enough however, is that the Dutch consumer

organizations refused to take part in this covenant. The covenant of 2006 stimulates voluntary actions that improve a 'healthy life style', including healthy food and fitness. Younger and elderly people seem to be the target of those programs. However, the minister of health want to give the highest priority to prevention and therefore he will propose a system of reimbursement of costs made for health and fitness programmes, so they will paid by public money. (Antwoorden op de vragen van de vaste commissie voor Volksgezondheid, Welzijn en Sport, over de kabinetsnota *Langer gezond leven; Ook een kwestie van gezond gedrag* (Tweede Kamer, vergaderjaar 2003–2004, 22 894, nr. 20).

Health Policy: Insurance Companies

The structure of the health assurances system in the Netherlands is now so organized, that assurance companies also give reduction of premiums, but not in the basic part, which is common to all companies, but in the additional assurances schemes. In these last schemes, companies are not obliged to accept everyone and they can differentiate sharply between what they call healthy and unhealthy persons. Moreover, they want all to incorporate health prevention measures, like fitness and sport courses; according to the present minister of health this should also happen with the basic part of the health assurance system. The companies mostly agree with the liberal Minister Hans Hogervorst (of the second cabinet Balkenende, 2004–2007); he delivered a speech on 14-04-2005, in Rotterdam, saying: 'I don't think that there exists something like a right on an unhealthy life. This don't sound very liberal, but I believe that one can't bring together living a life of risks and becoming ill and accordingly expect that one can use our health care system.'

Industry and Retail

Most large food companies are participating in the self-regulatory organization or Covenant, since 2006; to participate costs quite a lot, so small scale companies can not afford to participate (Dagevos and Munnichs, 2007). The covenant stresses individual responsibility of consumers and stimulates consumers to exercise more, and to eat healthy by a self regulatory system of branding. The system uses phrases like 'I choose consciously' and 'the healthy choice'. It is striking that for example cucumber, according to all scientific criteria a very healthy product, don't get the approval of this system. Packaged soup and other processed food get the approval and many products with as yet not proven health claims, like Actimel, because in their category they are less unhealthy; it would be more integer and transparent if the system used phrases like 'the healthier choice'. The organization is therefore seriously flawed and it remains to be seen in how far consumers trust the system.

NGO's

In the Netherlands there is not an effective organisation with the same kind of political strategy as the American *National Association to Advance Fat Acceptance* (NAAFA). In Chapter 4 we already mentioned the Dutch counterpart for the NAAFA, the 'Formidable Movement' (Beweging van Formaat), which is a much smaller organisation. It thus appears that a consistent campaign for fat acceptance cannot be pursued by organisations that strive to cater to the needs of the majority of obese and overweight people.

NAAFA's rejection of the disease label of obesity can be contrasted with the more ambivalent viewpoint of the Dutch Obesity Association (Nederlandse Obesitas Vereniging), which endorses the status of obesity (and overweight) as a disease on rather pragmatic grounds: 'Within the Dutch Obesity Association we prefer to refer to overweight as a chronic condition, because somebody who has gained overweight will only very rarely lose it again. Treatments have very low percentages of success.' (Dutch Obesity Association website: www.dikke-mensen.nl). Here the disease status of obesity (overweight) is supported not to argue for the urgency of treatment but to caution against unrealistic expectations of treatment! The Association apparently does not want to make a strategic choice for 'fat acceptance' only: 'For the Dutch Obesity Association it does not matter [. . .] whether you have accepted your weight or whether you engage in a daily struggle with the scales. We are at your service' (Dagevos and Munnichs, 2007). Nonetheless, some board members of the Dutch Obesity Association share the main tenets of the counter discourse on obesity (see Jeurissen and van Spanje, 2001). The association wants to correct biases of overweight people, although is doesn't want to idealize obese people and to neglect the physical and psychological problems they have. There are not against medicalisation or geniticalization, mostly because it rehabilitates their own respectability when it is shown that being obese is not their personal fault.

Schools

In the Netherlands schools mostly do not organize meals for the approximately 750,000 children that visit them daily, but they still have considerable influence on eating patterns of children, for example by organizing what they call a kind of in between at the middle of the morning, mostly around 11:00. This 'n between' stimulates kids to bring with them chocolate bars, chips and energy dense drinks. Schools also organize school milk for the lunch, thanks to the strong lobby of the milk associations that have a lot to say in what type of milk and how much.

Parents have started school movements like 'Time for eating' to organize better and more informative school menu times, by introducing cooking lessons during lunchtime. Others are busy in getting kids more exercise, by paying attention to school playfields and safe bicycle pathways to and from schools (Tijdvooreten.nl). However, these are initiatives from below and initiated or facilitated by low level governmental agencies.

Experts on Obesity and Genomics in the Netherlands and the Three Discourses

We organized a round table discussion with several experts on obesity in the Netherlands in which we asked their opinion about the three discourses/ constellations and about future scenarios *(June 2003).* The science scientific experts were from biology and human genetics; community genetics and epidemiology; nutritional research on metabole syndrome and cell research; population genetics and genetic diversity and finally genetics and pharmacogenetics. We also invited the president of the Dutch Obesitas Vereniging, a voluntary organisation of overweight and obese people.

The Three (Plus One) Discourses

We presented first the three discourses which ascribe a specific meaning to obesity, point out causes, remedies and responsible actors, lay down the rules for what can be said and what cannot. Discourses are not simply factual descriptions of existing states of affairs. They have a practical point in so far as their diagnoses locate responsibilities and accountabilities, and indicate the direction for finding solutions to this problem. All three agree that obesity constitutes a pressing problem, but then continue by focusing on different causes of and solutions to this problem. The first discourse centres around individual actions (behaviour), the second gives centre stage to environmental influences, and the third discourse focuses on biological causes in the body. As a result, discourse I individualizes and moralizes; discourse II moralizes but does not individualize; and discourse III finally individualizes but does not moralize.

Response of the Experts

The science experts agreed that the three discourses covered the Dutch landscape rather completely, but there were some doubts about aspects, like the lack of differentiation between genetics and genomics (see below), the shifting meaning of responsibilities and the role of new practices, like screening and the emergence of new patient and consumer groups, like fat people. They also liked the easy discernability of the three; so one can speak with respect to the first discourse of individualisation, with respect to the second of politicization and with respect to the third of biologicalization.

The community genetics expert argued that responsibility for public health is very fragmented organized compared with the USA (by Centres for Disease Control and Prevention, CDC; www.cdc.gov), and United Kingdom has the Department of Health (DH; www.dh.gov.uk). In the Netherlands we have the Gemeentelijke Gezondheids Dienst (GGD; Municipal Health Service), het Rijksinstituut voor Volksgezondheid en Milieu (RIVM) and the National Instituut

voor Gezondheidszorg en Ziektepreventie (NIGZ; National Institute for Health and Prevention). It is very unclear which institutions in the Netherlands have responsibility for prevention. Some insurance companies like Achmea (Achmea Health Centers) organize on a voluntary basis already preventive activities.

For many individuals it is often very easy to discriminate fat people, because you feel morally superior in morally disapproving of fat people. This means that the first discourse that stresses individual responsibility is strongly anchored in daily life of people and will not easy be changed. Others stressed the differences between ethnic groups in approving or disapproving thin or thick bodies.

Most of the experts underlined the future of genomics is more uncertain than many think. It is probably not the case that genomics in the end will produce for everyone in particular a clear message how to life healthy. The research is extremely difficult and costs a lot of money which most government and companies are not willing to pay. There is now interesting research on monogenetic afflictions but most diseases are multifactorial.

The difference between genetics and genomics was also extensive discussed. Most did agree that genomics compared to genetics is a large scale research enterprise, but also that genomics emphasises the interaction between genes and environment and also life style, which also means that interdisciplinarity and complexity is at the core of genomics.

The Future of Genomics and Obesity

First, the experts made it clear that in the Netherlands there is a rather strict regime with respect to screening of the population, In fact, only under very restricted conditions is such an enterprise thing possible. But the experts also stressed that familiar research can do a lot. Indeed, prevention is rather neglected in the Netherlands, and here again only preventive research is possible when there is some outlook on a therapy. Preventive research on nutrition is very costly and done only by a few in the world. This implies that the hopes a fast application of genomics results in health care or in coping with obesity are utopian.

According to the patient group, the introduction of genomics can be a relieve for obese people because they eliminate the bases for blame or guilt.

More and more the body is seen as something to be managed (60% of the women and 50% of the man is dieting according to one or another scheme). The relationship between private and public health is seen by most an important item, where slowly the emphasis is shifted towards the individual. In the future more privatised health care will be delivered, with its concomitant effect of more responsibility to private individuals.

However, the professions can also concentrate more on prevention and in particular general practioners could be more alert to incorporate food and life style recommendations on the basis of genetic and genomics services in their daily practice.

More liberal ruling of screening is not seen as a realistic option in the near future, as is more strict government intervention to decrease the number of obese people.

Conclusion

In the Netherlands the attitude towards food as an health item is dominant in one life- and food style (app. 25% of the population), and in the other styles, food is more connected with being social, responsible, pragmatic or self-determined. For strategies to implement (nutri) genomics products, services and other innovatory devices it is therefore questionable in how far an orientation exclusively toward health can influence adherents of these other life styles.

With respect to the expert discussion, the three discourses were seen by the experts as useful tools in structuring the field of obesity, but they had their doubts about fast applications of genomics services and products in Dutch health care system. Individualisation, Politicalisation and Biologicalisation seem to be relevant catchwords of three different approaches. However, all experts stressed the emergence of new responsibilities, new practices, and new groups involved in the emerging services and products. They also underlined the difficulties with undertaking research, in producing practical applications, and with regulating new responsibilities. Finally, the relationship between public health and private responsibilities was put on the agenda; we will tackle this issue in Chapter 13.

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Chapter 11
Obesity and Genomics in Italy

Mara Miele

Introduction

The chapter reviews and summarizes the Italian debate on the main causes of obesity and the current initiatives adopted by the Governament and private initiatives to tackle the problem. The first part gives an overview of the sitaution of obesity in Italy. The second part of the chapter reports on expert opinions on the possibility to address the problem of obesity through different approaches. This part attempts to review and describe the way in which Italian experts and practitioners view the problem of rising rate of obesity in the Italian context and their opinion on the possible ways to addressing it through cure, prevention, and regulation. The three constellations of responsibilities and causes, as described in the previous chapters in this book, have been used to prompt a discussion and to cluster the different approaches in a discussion with a group of Italian experts,[1] addressing more specifically the possibilities opened by the genomics approach to obesity.

Overview of the Situation of Obesity in Italy

Much has been written about the world-famous Mediterranean diet of which Italy is its prime representative.[2] Fresh vegetables, legumes, fresh fish, cereals and low quantities of meat products used to be the norm in most Italian households until not very long ago. Carol F. Helstosky (2004) gives an interesting account of the evolution of Italian cuisine and how specific notions of Italian food have spread in all Western countries in recent years. This author, by chronicling the period from the mid-19th century to the present day, argues that politics dramatically affected

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[1] A workshop with 20 Italian experts in the field of cure and prevention of obesity was held in Florence in May 2004.

[2] Visser et al.

M. Korthals (ed.), *Genomics, Obesity and the Struggle over Responsibilities*,
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the nature of Italian cuisine and food habits. Contrary to current perception, the Italian diet was inadequate and unchanging for many decades. Relying on detailed accounts from scientific specialists, domestic economists, government officials, and consumers, Helstosky shows how the poor diet of a large portion of the Italian population gained importance in the political debate and, finally, became a target of government intervention. As successive regimes liberal, fascist, democratic struggled with the question of how to improve peoples eating habits, their actions decisively and unintentionally affected what and how much Italians ate, shaping not only the foundations of Italian cuisine, but also the nature of Italian identity. It is therefore a sad irony that after centuries of food scarcity (Montanari, 1996) and almost a century of political action to tackle malnourishment, in the last few decades obesity is showing such rapid rates of growth in Italy, especially among its youngest population (Giordani, 2002; La Repubblica, 2003; Piattelli, 2004).

In fact, obesity is in Italy predominantly associated with children and teenagers, who show one of the highest obesity rates in Europe. Over a third, 36%, of all children in Italy were overweight or obese (OECD data 1998–2001), higher than Spain (30%), the UK (22%) or the USA (15%). Adults in Italy, on the other hand, show (together with France and Sweden) the lowest obesity rates of 9%, compared to the 65% present in the USA, although data largely depend on the definition and source used (see below).[3]

Recent studies of obesity in Italy give clues to some emerging national trends. The geographical distribution of obesity seems to indicate that being overweight is more common in the south of the country than in the northern regions (Barbagallo et al., 2002). This is in contrast with the observation that the so-called Mediterranean diet is disappearing more rapidly in the north of Italy, giving way to increased consumption of meat, dairy products and animal fats (Barbagallo et al., 2002). In their study of a rural village, Ventimiglia, in Sicily, Barbagallo et al. (2002) found that 75% of all adults in the village are overweight or obese. Of particular importance seemed to be the situation of early post-menopausal women, less than 10% of whom showed a normal weight.

Another study in Sicily, conducted by Perra et al. (2002) on the nutritional status, dietary habits, physical activity and self-perceived body image of pre-adolescents in Catania found that 27% of these children were overweight and 7% obese. Similar rates of obesity were found in a study of school children in Liguria Ciangherotti et al. (2003, see below). A study of pre-adolescents (10–15 years old) in Benevento, Campania in the south of Italy also found a high prevalence of body weight disorders: 27% were overweight and 11% obese (D'Argenio, n.d.)

Obesity is in Italy inversely associated with socio-economic position, as is in other industrialised countries (Stunkard, 1996). Vescio et al. (2001) surveyed a sample population in four rural municipalities in the province of Latina, Centre of Italy about 100 km south east of Rome in relation to cardiovascular risk factors. They

[3]For example, D'Amicis estimates that overweight rates among Italian men reach 45% while those for women are about 30% (D'Amicis, 1999 cited in AIAB, 2002).

Table 11.1 Obesity in children (8–10 years old, weight excess >120%) in various regions of Italy

Area	Year	Number	Boys(%)	Girls(%)	Boys and Girls(%)
North-East	1992	1523	23	13	16
Piedmont	–	12174	–	–	10
Milan	1986–1988	12354	14	12	13.4
Abruzzi	1992–1993	1021	25.8	23.5	23.5
Lazio	1999	22223	35.7	33	34.4
Bari	1990	786	20.2	28	23.9
Cagliari	1999	1238	24.5	17.9	21.2

Source: Sartorio (2003)

found that the higher the prevalence of obesity, the lower the grade of employment and level of education. Obesity was more common in women, especially farmers and housewives as opposed to professionals or those with higher education levels. For men it was also found that obesity was much more common among those at the bottom of the socio-economic scale.

Obesity and excessive weight in children is especially worrying because of its strong association with being overweight or obese in adult life of up to 80% (Ardizzi et al., 1996) as well as increased health risks linked to this condition, including developing chronic diseases. Some children are already developing what used to be considered 'diseases of old age' such as type 2 diabetes and heart disease (IOTF, 2005) (Table 11.1).

In this respect the Italian context presents some interesting contradictions. Being overweight or obese is more common among boys, who at the same time are more likely to exercise than their female counterparts. In a study of overweight and obese school children in Liguria, Ciangherotti et al. (2003) found that 36% of the third year boys surveyed were overweight as compared to 28% of the girls but that boys were more likely to practice sports (though the difference was not found to be significant). There seem to be other factors than just exercising that also influence obesity rates, for example, a predominantly sedentary lifestyle.

Both sides of the equation, food consumption and energy expenditure, are important. Studies focusing on the former have indeed identified changes in food consumption over the last few decades with a constant increase of the calories pro-capita from the end of World War II till the nineties.[4] Even in places where the Mediterranean diet is still observed, such as in rural Sicily in the village of Ventimiglia, cases of body weight disorders affect 75% of the adult population (47% overweight and 28% obese), way higher than the national average for that year (31.6% overweight and 6.5% obese). Given that food quality in this village is not an issue, the authors conclude that the increasing number of weight-related problems in the study population must be attributed to a greater quantity of food being consumed; or at least, greater than the energy expended (Barbagallo et al.,

[4] See Miele and Parisi, 2001 for a discussion of this issue.

2002). But in the last decade the per-capita food consumption has decreased, while obesity rate has increased.

Specific studies conducted among the elderly in Italy also show interesting results. Melchionda et al. (1990) in a study that covered various localities in the north, centre and south of Italy, found that BMI was inversely correlated with age among the elderly aged 65–95 years old.

A recent survey conducted by the Coni-Istat[5] has confirmed a widely shared opinion on the increasing of sedentary lifestyles of children and adolescents in Italy. In the last 8 years (between 1997 and 2005) the number of children and young adults doing sports has dropped dramatically, with a reduction of 1.2 Millions people age 15–24 doing any sport on a regular basis. This incredible drop is partially due to the low birth rate (Italy has one of lowest birth rate in Europe), partially is due to the fact that the children of the immigrants are not integrated in the system and mostly cannot afford joining the sport clubs, but it is also due to the fact that a growing number of adolescents, between 11 and 14 years old, stops doing any sports and prefer other activities for their leisure time (mainly watching sports on TV (!), videogames, listening to music and other sedentary activities). In Italy only 20.9% of the population practices a sport regularly, 38.5% practices sport irregularly, and 40.6% of the population does not do any sport (Coni-Istat, survey, in La Repubblica, 22/04/2006).

Research on Obesity in Italy

Interest in obesity in Italy is growing among scientists, as is illustrated by the expanding number of research studies available on the subject. Research addressing obesity in Italy can be divided between studies that aim to assess the scale of the problem at the local level; those studies that deal with specific age groups (generally these also focus on a specific locality); research linked to the nutritional habits of particular groups of people, generally specific age groups (e.g. school children) or a locality (e.g. a village) and clinical approaches to treat obesity, in particular, studies that assess the effectiveness of particular interventions. Some comparative studies that cover different regions with the aim of presenting a national view of the problem also exist (e.g. Melchionda et al., 1990) but there is as yet no definitive national study on obesity and weight-related problems that presents a general overview of the problem of obesity in Italy.

Some studies address obesity for specific age groups. This is the case with the research conducted by Melchionda et al. (1990) who compared their own data on the epidemiology of obesity in the elderly with existing data for elderly subject gathered during the 1980s. As was reported above, they found that *within the elderly group of people* age was inversely correlated with obesity.

An increasing number of researches focus on children (see e.g. Carruba, 2003; Ciangherotti et al., 2003; Sartorio, 2003; Viberti, 2003), given the worrying high levels of childhood obesity recorded in Italy. A recent multi-centre review of eleven

[5]La Repubblica, 22/04/2006

different paediatric departments assessed the success of obesity treatments for children (Pinelli et al., 1999). The authors of the report found that drop out rates were very high as less than 10% of those who started treatment remained in treatment after 2 years. They also note the high level of children who did not return after a first visit; among the obese, 70% of boys and 58% of girls did not want to continue with the treatment following their first visit. Pinelli et al. (1999) conclude that intervention in nutrition is insufficient for curing obesity and that family involvement for effectively address changes in lifestyle could prove crucial for the success of the treatment.

Other studies focusing on the children aim to assess the general levels of obesity, usually within a specific locality. This is the case with the study carried out by Menghetti et al. (1993) who measured obesity and hypertension levels in a high school in Rome. They found relatively low levels of obesity (6.9%) and similar levels of hypertension (6%) although what is interesting in their study is precisely the relationship between the two conditions. Almost all of those found to suffer from hypertension were also obese (Menghetti et al., 1993).

The relationship between weight-disorders and socio-economic position has also attracted some attention (see Vescio et al., 2001), although the focus on specific localities in most of these studies preclude the development of a wider national picture in relation to obesity and overweight. Information and analysis related to national trends are usually put forward by journalists rather than scientific studies.

The development of a clinical response to the problem of obesity and overweight, especially in children, is an area that is attracting growing interest, especially by general practitioners and specialists alike (e.g. Invitti, 2003; Scaglioni, n.d.). Specialists' centres for the study of obesity have also been set up. The Centro di Studi e Ricerche sull' Obesitá (CSRO) – or Centre for the Study and Research on Obesity was established at the University of Milan and advocates an interdisciplinary approach to understanding obesity, one which includes socio-economic and public health issues (Donino, n.d.).[6]

Addressing Obesity and Initiatives in Italy

In a recent national workshop on obesity (held at Cattolica University of Rome, 30–31 March 2006) there has been a general consensus that the biological cause of obesity (and its associated pathologies) is the *epigenetic*, which is the gene expression in presence of nutritional *stimula*, much more than genetic mutations and that the diffusion of sedentary lifestyles and incorrect eating habits (too much

[6]The aims of the research centre are to: Deepen the knowledge on the pathogenesis and meaning of obesity through the study of the mechanisms involved in the regulation of eating habits, the accumulation and dispersal of energy; Deepen the knowledge on the various therapeutic approaches to obesity with particular reference on the role of medicines; Promote and coordinate initiatives to collect information to identify characteristics correlated with specific risks of morbidity and mortality; Contribute towards raising awareness and towards the correct scientific information on the importance of obesity as a public health problem; Identify possible interventions to prevent obesity and its complications.

high calories foods) are the main causes of obesity and its associated pathologies (Prof. Geltrude Mingrone, in Cattolica News).

Looking at the Italian context we can say that the approaches aimed at tackling obesity are generally divided between those who see individuals as responsible for their health (and as empowered with agency to change their lifestyle in the broad sense), and those who tend to blame exogenous negative influences such as the 'McDonaldisation' of national food cultures, affecting the consumption of food (Hale, 2003). The latter implicitly assume that people are n-ot just unwilling but also powerless vis-à-vis these negative external forces associated with economic, social and cultural globalisation. There is also a minority of approaches that stress the role of genes in leading to obesity or eating disorder, thereby implying that change can only start through technological advances in the medical sciences and not from individual or institutional actions, as seen in the introduction, but Italian research in this area is very limited and never part of broader recommendations for specific intervention. Examples of this approach can be found in some recent studies of functional foods, as in the case of the research on Sicilian red oranges, which were found to contain a special bioactive substance that can be useful for fighting obesity (Almada, 2005) and on the research on meal replacements, even though the latter is inconclusive. A study by Keogh and Clifton (2005) suggests that controlled as well as not-controlled studies to date cannot provide us with sufficient evidence to suggest whether meal replacements are a viable long-term strategy for treating weight-related disorders.

These different approaches to tackling obesity largely depend on what the main cause of obesity is thought to be – genetic, environmental or behavioural, the last one being more commonly accepted by the Italian scientific community. Depending on these underlying assumptions, approaches to tackle obesity can be differentiated depending on their immediate target or assumed generator for change, whether this is the individual, the wider socio-economic and educational environment (institutional), medical know-how and finally the national legal framework. The ultimate aim of all these initiatives is to decrease obesity rates or at least to curb its rate of increase but the means for achieving this differ.

The main thrust of public initiatives to tackle obesity in Italy has so far been limited to information campaigns, mostly aimed at increasing knowledge about correct nutrition. The Italian Minister of Health[7] declared the prevention and decrease of obesity as one of the priorities for his agenda and developed a specific project on obesity within the National Health Plan for 2002–2004 (Epicentro, 2005). A think-tank estimates that every year obesity and problems associated with it costs the government at least 22.8 billion Euros, of which 64% are for hospital recovery Epicentro, (2005).

To address the growing obesity rates the Minister set up various commissions to deal with the problem and also promoted several information campaigns aimed at improving the nutritional education of school children (Donino, n.d.). Two different

[7]Dr. Girolamo Sirchia, Minister of Health between 2001 and 2006.

information campaigns were specifically target to families with children from 0 to 14 years old and to teenagers (Epicentro, 2005). The Ministry of Health has also been promoting the Mediterranean diet specifically as a way of re-introducing a balanced, healthy and nutritious diet in people's everyday food practices which also has the potential to decrease obesity rates in Italy[8].

The Ministry of Health also recognises the importance of food education and that food habits are formed from a young age, therefore, in collaboration with the Ministry of Public Education, has launched education programmes for schools to promote healthy eating, a revision of the guidelines for the menus of the school canteens (decrease in overall calories) and special day events in the classrooms and cafeterias(Donino, n.d.).

However, the main educational initiatives in the area of food education and prevention of obesity are lead by the Regions in the organisation of the school meals. The Tuscan region, as well as Emilia Romagna represent the earliest and most advanced initiatives in this area (Miele et al., 2005).

In Italy school catering was established after World War II as an instrument to compensate children's nutritional deficit. However, its role has changed over time, and it has acquired more and more importance. As early as 1974, school meals became to be conceived as part of the right to study[9] and as a public service. In recent years, food education and orientation to consumption have been included among the responsibilities of the School Institutes (EEC Document n. 1960 – 16/11/95 'Priorities for consumers' policy 1996/1998 and Law nr. 162/90 and Directive 600/96').

Today the majority of Italian schools (mainly pre- and primary schools) adopt the so called 'full time' system, with lessons given both in the morning and in the afternoon.

Thus, a large number of students have lunch in the catering structures. These are generally located inside the school building, where meals are served by qualified personnel to students sitting around the tables with their teachers.

Meals consist of different courses: a first course (generally pasta or rice), a second course (beef, veal, poultry, ham, fish, and cheese), vegetables, fruit, bread and drinks.

Menus are repeated on a 6 weekly basis and are designed by a committee (which includes nutritionists, paediatricians, hygienists, parents' representatives, and kitchen and school representatives) on the basis of the nutritional parameters indicated by the National Institute of Nutrition (max calories intake, max fat, sugar, proteins, minerals etc). Menus also change twice a year, in the wintertime and in the summertime, in order to introduce a wide variety of dishes that employ seasonal products, especially fruit and vegetables.

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[8](Ministry of Health, n.d.,)see http://www.ministerosalute.it/servizio/campagna.jsp?id_c=5

[9]Since 1974, the Regions and the delegated bodies (since 1977, the municipalities) have issued laws including 'provisions on school assistance and right to study' through which they plan and promote various services, including school meals.

Due to the key relevance of nutrition during the early years of life, the meal consumed at school becomes a training event which is very important for children, parents, teachers and the operators of school catering.

The meals at school provide an opportunity where children can learn to develop a well balanced and varied nutritional system that will prove useful for the rest of their lives. From this point of view, the school system is developing a *culture of nutrition and of prevention* of some pathology by promoting a correct diet, by adjusting menus, by supporting a Mediterranean diet that takes into consideration also the seasonality of food products in relation to local culture and to habits that are familiar to the families.

Usually the school meals are regulated by dietetic tables that take into account the nutritional requirements of young students on the basis of their age. Currently the Ministry of Health considers the Italian Society of Human Nutrition as the most authoritative reference for planning the dietetic tables and refers to the LARN that the Society has revised and updated in 1996.

Finally, the Minister of Health called in 2003 for Friday to be re-instated as an official fasting day (Hooper, 2003). Friday was in the past observed as a fasting day for religious reasons but Mr. Sirchia has argued that a break from the over-indulgence in abundant food would be good for Italians' health. Rather than having any scientific basis, such arguments has more a symbolic meaning in terms of raising the profile of the problem in the country.

Approaches to tackle obesity at the individual level focus on re-introducing a balance between energy intake and consumption (WHO, 2003b). The Societá italiana di nutrizione pediatrica -SINUPE (Italian Society of Pediatric Nutrition) produced a consensus document which include guidelines for a dietetic therapy for pediatric obesity (Scaglioni, n.d.). The document presents details of the nutritional education needed to achieve a normocaloric balanced diet. It therefore has the objective of supporting specialists who deal with cases of pediatric obesity. The authors specify that a therapeutic programme must include behaviour, medical and weight goals such as a gradual decline in BMI through weight maintenance or weight loss; new balance between energy expenditure and caloric intake; as well as others (see Scaglini, n.d. for further details).

A study sponsored by the Italian Ministry of Health which gives recommendations for the prevention, diagnosis and treatment of overweight and related diseases also focuses on the individual patient, partly because of limiting data-collection as well as action to general practitioners. However, the section dealing with prevention also includes environmental considerations and therefore suggests family-based prevention objectives, such as: Encouraging better buying, cooking and food preservation habits; Encouraging the consumption of fruits and vegetables because they are low in calories; Helping to reduce the time children spend watching TV; Encouraging regular exercise and more active lifestyle; Helping to reduce eating in front of the TV or alone; Fostering self-control in stressful situations.

It seems clear that these changes are unlikely to be brought about by the general practitioners alone. Rather, they need multi-agency cooperation to help bringing about a healthier environment at home, school and society at large, as recommended

by the WHO global strategy on diet, physical activity and health (see WHO, 2004 for details).

Medical approaches to tackle obesity aim to increase knowledge related to obesity and weight-related disorders as well as to develop medical responses to solving this problem. Obesity is now also gaining wider recognition as a serious multi-causal and complex problem among the medical profession and special centres have been set up to study the causes of obesity as well as to develop possible strategies to combat it (see Centro di Studi e Ricerche sull' Obesitá in the next section).

The development of the *LAP-BAND®*, first introduced in Europe in 1993, is one such example where technological innovation has provided patients with severe (morbid) obesity with a device to help them develop better weight management. It consists of an adjustable inflatable silicone band that is inserted in the patient's top part of her or his stomach. As it inflates, it gives the patient the feeling of being full, therefore limiting food consumption (Association for Morbid Obesity Support, 2005).

Interdisciplinary clinics are another plan proposed by the Ministry of Health with the aim of offering advice to obese patients. The Ministry proposes to place these clinics at public health facilities and hospitals and staff them experts able to offer advice on nutrition, psychology (cognitive and behavioural therapy) and a physician with expertise in obesity-related illnesses (Donino, n.d.).

It is also increasingly widely acknowledged that obesity, especially in children, is also fuelled by the food manufacturing industry that specifically targets children through its marketing (Lobstein and Dibb, 2005). The was also the main conclusion of study 'Does Food Promotion Influence Children? A Systematic Review of the Evidence,' was produced for the Food Standards Agency by Professor Gerard Hastings and his team at the University of Strathclyde Centre for Social Marketing. The market of food advertisement is 340 mil Euro in UK in a year. A second recent report was issued by The Food Commission, 'Broadcasting Bad Health: Why food Marketing to Children Needs to be Controlled' (2003), with extensive proofs of the risks of marketing junk foods by KFC, Burger King, McDonalds etc.

This recognition has led some organisations to aim their efforts at changing the national legislations, especially in relation to tightening the regulations on food advertising, for foods target to children. Some organisations also put pressure on the food industry to improve standards of the food it produces for children, such as improving ingredients and decreasing the use of the sugar content and other harmful substances. Introducing tighter regulation of food marketing as well as a clearer labelling system so that consumers can easily identify foods which are high in fat, sugar and salt are policies advocated by the International Obesity Task Force (IOTF, 2003a, b). The UK and Sweden are two examples where lobbying is currently being undertaken to introduce tighter regulation especially for food marketing which targets children.[10] California is now breaking a record in history as Gov.

[10]The 'traffic light' labelling scheme has been recently introduced (2006) in the UK to indicate the risk related to the high content of calories of each food.

Arnold Schwarzenegger gets ready to sign a law limiting the sales of soft drinks and junk food on state school campuses (Griffith, 2005).

Private initiatives can be divided between awareness-raising not-for-profit campaigns and private companies who provide products or specific services for the obese and the overweight. Among the former, one can find various non-governmental organisations that seek to provide support to overweight and obese people as well as those that have initiated campaigns to raise awareness about weight-related problems, nutrition and following a balanced life-style. Other organisations such as the Italian Obesity Society (SIO)[11] conduct research on obesity-related issues and organise training for specialists. They also produce a newsletter with information about conferences and national initiatives (see website).

ABA is a not-for-profit organisation aimed at providing support for people who suffer from weight-related disorders, including obesity.[12] It works by encouraging people to get the professional help that is often available for their specific illnesses but that many patients often refuse to take. They also offer counselling and are present in twelve cities in Italy.

Other initiatives consist of self-help groups that encourage people to tackle their problems in a group setting, following a self-help philosophy.[13] These do not seem to be regulated but are part of the Association for Self-Help (AMA).[14]

The international network of Danone Institutes, with a centre also in Italy, have a programme on early child nutrition 'Childhood Obesity: Early Programming by Infant Nutrition?' which recognises the crucial role played by early nutrition for the development of weight-related programmes. Building on existing evidence which suggests that formula-fed infants are more prone to obesity, the project aims to pilot a research project on the precise influence of infant formula as well as parental attitudes for developing obesity later on in life.[15]

Italian Experts' Opinions on Responsibilities and Responses to Obesity

Currently in Italy, like in most Western European societies, obesity is perceived as a fast growing *medical* problem as well as an eating disorder.[16] However, problems of being overweight or obese have been considered a problem (aesthetical, psychological) before it became a medical problem.

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[11] Societá Italiana dell'Obesitá, see http://www.sio-obesita.it/

[12] see http://www.bulimianoressia.it/site/chisiamo.asp

[13] http://digilander.libero.it/automutuoaiuto/dimagrire_insieme.htm

[14] Associazione di Auto Mutuo Aiuto see http://digilander.libero.it/automutuoaiuto/index.html

[15] http://www.danoneinstitute.org/EUchildhoodobesity/index.php

[16] Data from the National Institute of Statistic in Italy (ISTAT) in year 2000, show that in a population of 4,600,000 young women, aged between 12 and 25 years old, there are about 138,000 cases of anorexia nervosa and 250,000 bulimia nervosa. Maurizio POMPILI, Ann IST Super Sanità 2003; 39, 2, 275–281.

Here we will discuss how the Italian experts and practitioners perceive and frame the problem of obesity and what kind of solutions they envisage. The analysis here presented of the Italian experts opinion on Obesity is based on interviews and group discussion carried out with a group of 20 experts from several regions in Italy, all of them renown in their field of expertise and engaging in different practices, ranging from surgical intervention for stomach reduction/bypass in the cases of extreme obesity to the representatives of local agencies/local authorities working in the field of nutrition and involved in educational programmes for correct food education.[17]

From the group discussion emerged the following discourses about the prevention of obesity through intervention in schools with educational programmes and children involvement (*Education);* the cure of obese people (*Changing behaviour, no diet),* to broader concerns about the implication of future scientific knowledge (*Genomics*) and technologies in this field.

Food Education and Involvement

A concern widely shared is the increasing 'obesogenic' environment and especially the nutritionists working with children in schools and involved in educational programmes share an awareness of the strong influence of the environment (junk food, watching TV, video games, advertising, increasing number of fast food outlets,) in the adoption of sedentary lifestyles and high caloric diets among young people. The field of food education is seen unanimously as a major area of public intervention, especially through the introduction of healthy diets and the revision of nutritional guidelines for the school meals.

Changing Behaviour, No Diet

The majority of Italian experts who participated in our group discussion framed the problem of obesity as a problem of the 'individual' in relation to her/his environment and identified lifestyle and more specifically *behaviour* as the main reasons for obesity. The main concern expressed by the experts was the psychological impact that this condition has on obese individuals, mainly the moralisation of the body size and the stigma associated with obesity in Italian society. They tended to underline the role of social factors in affecting the psychological impact of obesity. Negative messages about being overweight and a strong anti-fat bias are widely spread in the Italian media, especially Italian commercial TVs, where an image of eternally young, fit, glamour women who generously show their perfectly slim bodies is highly promoted. This body image and a culture of high investment in appearance, fashion and fitness is dominant in Italian society in general, or at least so

[17]The interviews/presentations and group discussion took place in 1 day workshop in May 2004 in Florence. All presentations and the group discussion have been recorded and fully transcribed.

it is perceived by the majority of the participants interviewed, with negative consequences of stigma and blame of the obese individuals, especially women,[18] who are perceived as 'weak, lazy, sloppy, incompetent and emotionally unstable'.

The stigma associated with obesity is higher in the North of Italy and less perceived in the South, where different aesthetic canons and acceptance of bigger body sizes, especially for men, seem to survive. This difference in perception is quite remarkable between the Northern and Southern regions and, in some cases it might also leads to a lack of understanding of the problem: overweight or even obese children in the South are often perceived as *healthy and plump* and no action is taken to redress the situation.

In general the group of Italian experts echoed concerns expressed by Friedman and Brownell (1995), that 'obesity can have acute psychological consequences' and that the life dissatisfaction, social liabilities and body image distress produced by obesity form barriers to emotion regulation that, for both biological and psychological reasons, lead to increased eating (Swartz and Brownell, 2001, 43). This view is well exemplified by the following statements:

> My initial training was in behaviour treatment in the University of Minneapolis, in Minnesota and this mostly informed my way of treating eating disorders [. . .]. I would like to underline that talking about behaviour treatment what you really do is to influence behaviour of people, instead of prescribing diets, which means telling people which our results will be, how much weight they have to lose, how much they should weigh or what they should eat. We are more interested in the process with which we can reach these results. So, I'm not interested in diets, I'm fiercely against diets, it's about 25 years that I'm heavily shouting against diet behaviour because this is one of the main problems in eating disorders, which exactly produces eating disorders and other problems as well. I'm more interested in how do you get people to change their attitude, to change their behaviour and start knowing how to do things by themselves and not dominated by somebody who tells you what to do, but being autonomous and independent. [. . .]I've worked a lot on the application of behaviour therapy in the field of eating, eating disorders and obesity, but I've also worked on other theories like the motivation enhancement, transneuretical modes involvement and again what I'm really interested in is how do you get people responsible for their behaviour, how do we give them the ability to deal with the problem instead of becoming dependent from an institution, from whoever is good for them (at least this is what they usually think). So I very much work on giving tools to people to become better, to become self-controlled instead of being controlled from the outside. This means that they must understand their own environment, so what I worked also on is assertiveness, because there is no way you can fight obesity if you're not assertive. Our environment doesn't like people start eating less, so you really have to be very good on one side to defend yourself from doing excessive diets, on the other side to defend yourself from eating to much and you have to understand better what you really need: this is assertiveness. (B.B., DIDASCO)[19]

Other participants put more emphasis on the role of the diet, but all seem to share the view that the psychological component of the treatment of obesity is crucial

[18]There is a growing literature that point to the this bias results in stigma and discrimination (Puhl and Brownell, 2001).

[19]Founder and member since 1979 of AIAMC, Italian Association of Cognitive – Behaviour Therapy.

and they tended to agree on strategies of care/cure that start from identifying and addressing the 'discomfort', the 'depression', the 'stress' that might be at the root of the eating disorders (which might be obesity or anorexia or bulimia or binge eating disorder).

> [. . .] As far as the diet is concerned, you have to think of it in the critical way, always as part of the lifestyle. [. . .] The first step is to communicate the diagnosis to the patient, and you try to give all the responsibility in detail to the treatment team, including the patient: you have to share the rational of the therapy with the patient, you have to focus on objectives or goals with the patient, you have to highlight even his competences and where he can promote the change. Interdisciplinary means to include the patient himself/herself [in the expert team]. After this step, you have the re-assessment of the medical point of view. If this is not enough, you add some nutritional counselling [. . .](R.S., Centro Gruber)

Genomics

When asked about opinions on the future possibilities opened by the research on genomics the reactions where generally positive even though the development of this line of research is virtually non-existing in the Italian context. The possibility offered by this new line of research to free 'obesity' from social condemnation was identified as the most positive feature.

> If obesity is understood as a consequence of a genetic predisposition and can be treated through special products, the causes of the stigma associated with obesity are removed (obese people are not to be blamed for lack of will power, laziness or gluttony and lack or control, but they are to be treated as any other group of people with medical conditions (M.F.)

However a number of concerns associated with the possible development of genomics have also been voiced: ethical considerations regarding the possibility to affect the behaviour of the patients by disclosing information about their genetic make-up:

> I can see I think that you can use this model for any other kind of pathology [. . .] when these three components of behaviour, environment and genetics are so important. So, this is my first question, why did you choose obesity in first place? Then the other thing is: I think that the issue of ethical issues on genomics is true for everything, even for genetics. Now researchers have found that there some kind of polymorphs in some genes is responsible for a possible development of mental disorders, for the 'possible' development. . . so, what do you do? Do you tell people they have this polymorphism on their genes in order to do something about it? Or you don't tell them? And if you tell them you are affecting their life, so actually you are modifying the way in which their behaviour will be and possible the natural course of the disorder if there is a disorder there. If you don't say them maybe you are responsible of not preventing that disorder. . . so I think this is a very major issue when we are talking about these problems. (M.M.)

Appropriation by multinationals or other powerful market actors of this innovation and the technologies and products associated with it.

> I'm not a specialist in genomics and I don't understand so much about it, but what I feel in this field is that as we have seen in the past that any application of the treatments that

> come from scientific researches take at least 20 years (at least in Italy). So, it takes long time from when you find something that would be useful for treatments and actually when it will be really applied, and, by the way the money is less and less, so we may be not to expect to see any application for a great part of the population and if it comes to prevention is even worst, because the prevention costs a lots of many and does not give, apparently, anything in exchange what you can show. So, prevention programmes have started now to understand to they should create people who are more resistant to pressure and self esteem instead to tell children about diets. We know that 20 years ago and they start now to put in place these ideas. So, what I see now is: in this space of time, between you understand something about genomics and when you will apply to treatments I see that multinationals will be much faster and much quicker and they will use it against people. This is my idea as an expert on economics and organisations. Who has a lot of money and who can take really advantage of research is much quicker than our medical field and our school system. So I would see an ethical problem in understanding and in preventing the bad use of what you can understand about influencing behaviour of consumers and influencing behaviours of patients in the negative sense, and this has happened all the time. I think psychologists have been better used by multinationals in trying to sell their food rather than trying to prevent to become obese, for example. (B.B.)

Lastly, another ethical problem associated with genomics was identified, which is the possibility to exert 'the right to be different' (obesity is not necessarily associated with illness) or even the right to be 'ill'

> I think there is an incredible wide range of this kind of problems. I probably would like to raise another issue: have I the right to be ill? Have I the right to be obese? Have I the right to be suffering? For me in this sense Italy is very protective. I think we have a good quality of individualistic approach for life and, thankfully, I work in Italy. (R.S.)

Conclusion

In the Italian context obesity is an emergent problem especially for children and the most visible interventions are in the field of prevention and food education is schools (Miele et al., 2005). The emergence of an 'obesogenic' environment is seen as risky especially for children and adolescents, and initiatives for limiting the access of children to unhealthy foods (such as snacks and soft drinks in schools) or limiting the food adverts on TV at specific times of the day, when children are more likely to watch TV, have appeared over the last decade.

The psychological effects of obesity represent a focus of attention of the majority of the interviewed experts involved in the cure of obesity. Their approaches, even though might differ substantially, are mostly associated with initiatives/ therapies for changing the 'behaviour' and lifestyle of obese people.

The moralization of the body size in Italian culture is seen as a great source of anxiety and the dissatisfaction with body image of obese people has a negative impact on therapies.

While discussing on the possibility offered by the emergence of the genomics approach to obesity the opinions of the experts varied. The most optimistic view interpreted genomics as an opportunity to overcome the problem of the 'stigma' often associated with obesity in Italian culture. However many ethical questions

were also posed: who will be regulating this new development? Will it be just an opportunity for developing a market for new products? Is it going to lead to general screening that will reduce the autonomy of the individual to choose whether to be treated or not?

The whole discussion occurred in a very hypothetical state because at present time this approach to obesity is virtually non existing in Italy and it is not seen as part of the possible development in the near future, while the rapid increase in children obesity poses the question for workable and immediate interventions.

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Chapter 12
Holland-Italy: A Match Too Far? Comparative Analysis of Italy and The Netherlands on Obesity and Genomics

Michiel Korthals

Introduction

In this chapter we will concentrate on the comparison of our Dutch and Italian studies on the way the relationship between obesity and genomics is framed and managed in these countries, on the prospects of the application of genomics to obesity and on European aspects of the relationship between obesity and genomics.

For various reasons we have chosen to turn to Italy and to a comparative analysis of the Netherlands and Italy, after spending a lot of attention to the Netherlands. First, Italy is well known for its special attention for food and the way food functions in daily life: in Italy, so people say, one lives for eating and not eats for a living. This implicates that food, food production and the body are intrinsically connected in the typical Italian mind. Although one has to be careful with these general cultural traits: in the previous chapter we quoted already *Garlic and oil: politics and food in Italy* of Carol Helstosky, who clearly shows that this story of the national meaning of food for Italy is a rather short one, and is indeed constructed by several governmental measures after the first and second world war, to provide food security.

A second reason has to do with the fact that one of most cherished truths of food science, the healthy effect of the so-called Mediterranean diet, indeed has been discovered in Italy and Greece. Ever since Jean Tremolieres (1913–1976) travelled with hundred or so researchers to Crete to study with money of the Rockefeller Foundation the 'conditions of the transformation of a traditional economy into a modern, industrial economy' and made public his research into the positive effects of a diet with lots of vegetable oil, vegetables, fish, and wine, and a life style connected with common meals and sufficient physical activity, the Italians have been officially seen as very healthy. The Mediterranean diet indicates that Italians have a conscious food style connected with all other aspects of daily life, Due to this diet, they live longer in a healthy way.

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A third reason is that, as we have seen, obesity is increasingly a problem in Italy as well, both for adults as for children. Italy rank among the highest (with the other Mediterranean countries Greece, Spain, and Malta) the last decade with respect to the increase of obesity among children; a surprising fact taking into account the still wide spread Mediterranean diet. What could be the reasons for this trend? We will first put forward some reflections on the methodology of a comparative analysis. It turns out that a comparative analysis can't be done in a naïve way, because there are many pitfalls, in particular biased judgment can hamper to get good insight in the difference and similarities of different cultures. We do not presuppose that the Dutch and the Italian culture are uniform or frame their problems in the same way; we will however look to comparisons between phenomena and outlooks that are sufficient similar and simultaneous different, to give an idea of the different challenges that obesity can be for a certain culture. In this way one can learn from differences in tackling a problem.

In the second section we will reflect on the meaning of a comparative analysis and after this reflection, we will turn in the third section towards the European contexts and show that the changes in policies and structures encouraged in general a climate in which obesity could increase. In the fourth section we will undertake the comparative analysis.

The Meaning of a Comparative Analysis

In taking into account the Italian and Dutch experience with obesity through a short overview of the main features of framing the problem and of the solutions, we step into a comparative analysis, which needs some justification and reflection. One can compare two or more cultures by using a universal yardstick and the most frequent used yardsticks are as a matter of course the culture the one that compares is most acquainted with. This kind of comparison happens very often: for example one can compare how a certain illness in different countries is treated in hospitals, and than conclude in the country where the most hospitals treatments find place, that patient has best outlook for treatment. In this kind of analysis, the type of treatment that the researchers favour most is used as the measuring rod. The problem is here the measuring rod or the criteria that one uses: why should one's own culture be superior to others? In doing comparative analysis in this way, the ultimate motive is not comparing and learning, but putting cultures in boxes and showing that ones own culture is the best (Jasanoff, 2005).

However, this is not the only way one can perform a comparative analysis. It seems that the method of comparing cultures by using a universal yardstick, confuses comparability with commensurability. It is quite difficult to justify the claim that cultures are commensurable (i.e. can be measured by one yardstick) and most well known efforts often are easily undermined due to ethnocentrism of the yardstick. But it is a total different thing to claim that one can compare cultures in an effort to learn form their way of framing and solving problems. Comparing can have another meaning because it can be motivated as a learning process, which assumes

that one at least is open enough to see how other cultures formulate problems and solve them (or not). Consequently, if one indeed finds out that one culture formulates a problem in a certain way and tries solutions accordingly, one assumes that one can learn from these activities, for example by imitation or in a more balanced way, by taken the other culture as a kind of inspiration for measures in the first culture. Although one runs the risk of comparing apples with oranges by not taking into account the very special local circumstances of both cultures, one can take measures not to cover the differences.

Comparing in this last sense has other intricacies as well. It can not mean that one neutrally compares, stripping oneself of the own culture and standing naked as it where with the different cultures before ones critical eye (Haaften, 1996). Comparing is always partly partial, but tries to transgress as much as possible the biases of the culture one comes from. That comparisons can indeed succeed this way has as its proof the existence of successful translations and their assistants, dictionaries. However one can not neutrally jump from one culture to another, there is not a neutral standpoint form which we can compare different systems, so it still our comparison.

Obesity, as we have seen, is framed in various ways that differ substantially, however, all frameworks imply certain action perspectives and practices for people involved, and it is these practices that we are interested in. These perspectives and practices frame options and things not done, so we will analyze these.

Our focus will be the three discourses and the role of genomics in the two countries; how will the public react, and what the policymakers do. To start the comparison we will make a short tour through the European context of the problem.

Obesity in Europe

Obesity and other weight-related pathologies have increased in Europe in parallel with greater availability of high-energy food and a decrease of physical mobility due to the automation of many everyday activities. These factors have largely contributed to the unbalanced energy equation, i.e. larger energy intake and energy consumption than energy output (IOTF, 2003b). People in the industrialised countries of Europe have increasingly sedentary occupations and are also less physically active outside of work as preferences for leisure time lean towards watching TV or playing computer games. As car ownership increases there is less of a need to walk to work or even to the bus stop, let alone to cycle. Less energy is also spent at home where tasks such as food preparation or cleaning are automated while relying on central heating also decreases our energy expenditure since our bodies do not need to generate extra heat to keep us warm in winter. Sedentary behaviour has been highlighted as the major reason behind the epidemic of obesity (Kopelman, 1999). All these lifestyle changes are taking place in a context where people have greater access to high-energy food and greater quantities of it through expanding incomes (WHO, 2003a; Table 12.1 , Figs.12.1 and 12.2).

Table 12.1 Obesity and overweight male and female in the EU (adult population)

Country	Year of data collection	Males			Females		
		% BMI 25–29.9	%BMI > 30	Combined BMI > 25	% BMI 25– 29.9	%BMI > 30	Combined BMI > 25
Austria	1999	40	10	50	27	14	41
Belgium	1994–1997	49	14	63	28	13	41
Cyprus	1999–2000	46	26.6	72.6	34.3	23.7	58
Czech Republic	1997/1998	48.5	24.7	73.2	31.4	26.2	57.6
Denmark	1992	39.7	12.5	52.2	26	11.3	37.3
England	2003	43.2	22.2	65.4	32.6	23	55.6
Estonia (self report)	*1994–1998*	*35.5*	*9.9*	45.4	26.9	15.3	42.2
Finland	1997	48	19.8	67.8	33	19.4	52.4
France (self report)	*2003*	*37.4*	*11.4*	48.8	23.7	11.3	35
Germany	2002	52.9	22.5	75.4	35.6	23.3	58.9
Greece	1994–1998	51.1	27.5	78.6	36.6	38.1	74.7
Hungary	1992–1994	41.9	21	62.9	27.9	21.2	49.1
Ireland	1997–1999	46.3	20.1	66.4	32.5	15.9	48.4
Italy (self report)	***1999***	***41***	***9.5***	**50.5**	**25.7**	**9.9**	**35.6**
Latvia	1997	41	9.5	50.5	33	17.4	50.4
Lithuania	1997	41.9	11.4	53.3	32.7	18.3	51
Luxembourg		45.6	15.3	60.9	30.7	13.9	44.6
Malta	1984	46	22	68	32	35	67
Netherlands	1998–2002	43.5	10.4	53.9	28.5	10.1	38.6
Poland (self report)	*1996*	*n/a*	*10.3*	n/a	n/a	12.4	n/a
Portugal (urban)	Published 2003	n/a	13.9	n/a	n/a	26.1	n/a
Slovakia*	1992–1999	49.7	19.3	69	32.1	18.9	51
Slovenia (self report)	*2001*	*50*	*16.5*	*66.5*	*30.9*	*13.8*	*44.7*
Spain	1990–1994	47.4	11.5	58.9	31.6	15.3	46.9
Sweden (adjusted)	1996–1997	41.2	10	51.2	29.8	11.9	41.7

*Slovakia: IOTF estimate based on measured data.
Source: International obesity task force, London – March 2005

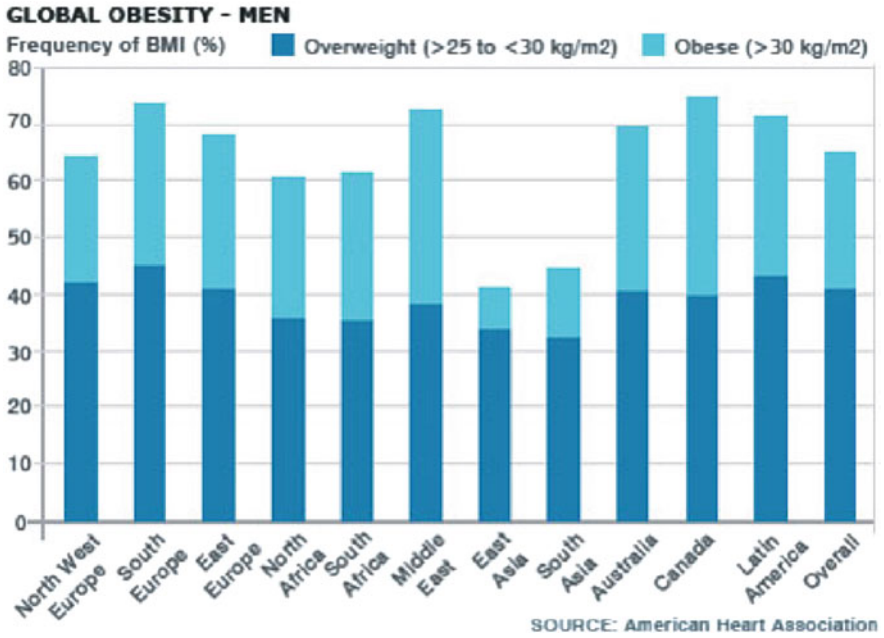

Fig. 12.1 Prevalence of overweight and obese men in the world (except US)

The increase in obese children is particularly worrisome, because these children will have much more difficulties to reach a normal weight than adults. Moreover, it turns that the countries that indeed are always mentioned as the champion of the healthy Mediterranean diet, are now the champions in producing obese children.

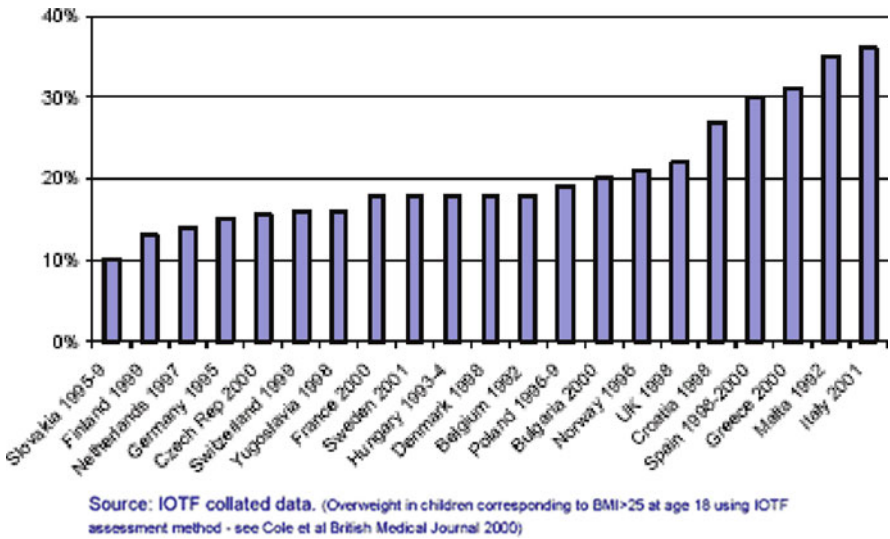

Fig. 12.2 Prevalence of overweight European children aged ~10 years by year

Italy is now frontrunner with more than 45% overweight children. This is quite a paradox; as we have seen and research into the reasons of this sudden outburst is not intensive. The paradox is even sharper, because there are even more obese children in the South of Italy, where there are less Fast-food restaurants and other components of the fast food life style, than in the North.

European Dimensions of the Rise in Obesity

Policies of the European Union have in both positive as in negative ways contributed to the rise in obesity in the European countries. Cheap, and energy dense foods have been heavily subsidized by the Common Agricultural Policy (CAP) of the European Union. As Lang and Rayner remark: 'The technology driven leap in farm productivity has been accompanied by a transformation of distribution systems, logistics and packaging which have made possible unprecedented availability of high calorie foods and ensured just-in-time availability for "snacking opportunities" in daily life.' (Lang and Rayner, 2005, 310). Sugar, animal feed and other staple products have been subsided or got tax relieves, to make them as cheap as possible. In Spain for example, the huge rise in meat buying and correspondingly animal protein use (from 13.5 to 30% in 2001) are for a considerable part stimulated by the low prices of meat due to feed subsidies. Although the CAP is developing into another direction towards a system of income subsidy instead of product outcome, it still has considerable influence on the food prices. Moreover, the CAP does not aim at health of the European inhabitants and is never assessed on its health impacts (CAP has also always subsidized tobacco industry).

Children in the European Union eat on the average140 g of fruit and 86 g of vegetable, much less than the prescribed amount of fruit and vegetable. It is however clear that the children do not know how much fruit and vegetable that is, and therefore have to learn what the estimates mean in daily life: they have to have lessons also on preparing vegetables, their parents should encourage them, and the products should be easily available. (Pro Children project, EU). The differences in Europe between the nationalities are considerable. In the Netherlands kids don't kid normally fruit and vegetables, but in Norway they get regularly fruit intake.

However, physical activities saving devices have also been heavily encouraged by European subsidies and policies, as for example by emphasis on digitalisation of education, like for example the increasing use of computers on school in contradistinction to physical exercise. But also more strictly labour saving devices have been encouraged, and in general private motorized transport has been subsidized more than public transport.

The European commission is conscious of these effects but has until now not really taken coherent measures to counteract the rise in obesity as becomes clear from several speeches of commissioner Byrne. Take for example the speech of *David Byrne*, called *Health, Nutrition and Labelling* (Speech/03/87, 19 February 2003): he first states that 'Economically, obesity constitutes a massive drain on

public resources.'... 'And if the obesity rate amongst European children continues to rise, the results could be nothing short of catastrophic. Life expectancy could fall while healthcare spending could go through the roof.' He then continues with 'Legislation cannot combat obesity. [...] The active involvement of a range of key stakeholders is essential for the development of clear, understandable, motivational messages to encourage positive behavioural change' [...] 'We also need to make sure that those consumers who want to make healthy food choices are given correct information through proper labelling and that they are not confused or misled by claims alleging certain health or nutritional benefits of the foods they buy.' 'We do not intend to prohibit the use of claims on certain foods on the basis of their "nutritional profile". This would run contrary to the basic principle in nutrition that there are no "good" and "bad" foods but rather "good" and "bad" diets'.

[NB: The proposal for a new regulation that the Commission adopted in July 2003 did endorse the requirement of an acceptable 'nutritional profile'!!]

In his speech of 2 October 2003, called 'Progress in building consumer protection' (speech/03/442), David Byrne said: 'While the food agenda has largely been dominated by safety questions in the past, now much more focus is rightly on the link between food and health.' 'In this regard, obesity and all its attendant health problems has emerged as potentially one of the biggest challenges facing individuals, society and policy makers.' 'We all have to acknowledge that in this area there are no easy solutions. We are dealing with lifestyle issues, matters of personal choice and cultural preferences, among others.' 'But yet we must be conscious of, and respond appropriately to, the public health dimension of this problem.'

Responsibility of government, civil society and industry is tackled by David Byrne in his speech of 8 July 2003 (Speech 03/349), called 'Food for Thought – Nutrition and Public Health Policy': 'We know that the factors influencing obesity are complex. They encompass genetic, societal and environmental factors, including, of course, diet and lifestyle.' [...] 'These measures, taken together [i.e. proposals for the regulation of nutrient and health claims and on the enrichment with vitamins and minerals, MK], amount to a major overhaul of European food labelling legislation with the aim of helping consumers to make informed choices about what they choose to buy.' 'But while such information represents an important enabling factor, it cannot in isolation lead to dietary and behavioural change. The Eurodiet and WHO/FAO reports, and other public health nutrition experts, all highlight the need for co-ordinated, multi-sectoral and population wide strategies.' (...) 'First governments and civil society need to ensure that health and nutrition is given the priority it deserves as indeed many within the European Union are actively doing. This includes the promotion of good dietary habits and the importance of exercise.' [...] 'Second the food industry has a responsibility to ensure that healthy choices become easy choices for their consumers, a point made by Dr Brundtland of the WHO, in particular with regard to children.' [...] 'The food industry must respond to this challenge by providing foods that meet consumers' expectations for taste and convenience while addressing today's nutritional concerns.' 'Whilst institutions can inform, educate and point out the benefits of eating healthily, taking exercise and

controlling weight, ultimately the responsibility for taking personal action lies with the individual.'

A more recent white paper of the EU, White Paper – A Strategy for Europe on Nutrition, Overweight and Obesity related health issues (2007) 279, May 2007 proposes a broad strategy, with attention for both food and exercise. Its starting points are:

> Tackling this important public health issue entails the integration of policies across the board; from food and consumer, to sport, education and transport. Obesity has higher prevalence among people in lower socio-economic groups indicating the need to pay particular attention to the social dimension of the issue.

Again, no stance is taken with respect to the multiple responsibilities of stakeholders involved.

As always with respect to obesity, exaggerations are trendy. So reported the Sunday Times of September 2, 2007, that according to the 'Health Chief of the EU', EU Health Commissioner Markos Kyprianou, that 'obesity is greatest health threat facing EU'. The journal stated: 'European figures show up to 27% of European men and 38% of women are obese' but it didn't give any references.

It seems as if the EU is taken measures according to three perspectives. It is providing information and structures for dieting citizens; it is stimulating citizens to do more exercise, e.g. by paying for advertisements during the Champions League, and it is subsidizing research into functional foods, and into the fundamental relationships between food, diet and the metabolic syndrome (by such large-scale programs like NUGO, Earnest, Aquamax, Diogenes etc.)

The Italian Situation

From the reports of the experts it shows that the appearance of overweight and obesity is not always an issue of the quality of the food. As the increase of obesity in the South of Italy demonstrates, an area very much still keeping up with the Mediterranean diet, quantity of food input does play a role and output. The south is indeed an area that is not held in very high esteem, and its socio economic status is not high, compared to the North. Moreover, it seems that in the South there is more leniency towards having a fat body.

Italy does not have a general national policy with respect to overweight and obesity, but the regions do have considerable possibilities to act and put several policies into practice. In particular the schools have a rather strong role in trying to prevent overweight, with their daily oversight of pupils. Interesting, because at least in tension with these disciplining practices, is the emphasis on enjoying good food and the care not to produce 'body image distress': the moralization of the body and the body size is prevented as much as possible. A good evaluation of these policies however could not be given.

The role of genomics does seem to be marginal. The general ethical problems like privacy, regulation, power of large companies, loom heavily.

The Dutch Situation

According to the Dutch Council of Healthcare and Care individual responsibility is the most important perspective in tackling life style diseases like obesity. Moreover, the Dutch covenant on overweight (Convenant 2005) stresses that 'overweight primarily is an issue of the individual'. It looks like that the Dutch policy is much more concentrating on the output side of the issue: how to get more Dutch people walking, moving in daily life, and not on the input side, the energy-intake.

The role of genomics in the Dutch situation is marginal as well; moreover, there are not programs that are directed in implementing policies with respect to the applications of genomics against obesity.

Comparison Holland Italy

Several things immediately strike the eye. In both countries there is a lack of coherent national policy, but in Italy, because of the more independent status of the provinces, we see that they in particular can implement a policy. In the Netherlands, the only national policy until now has been the initiative of the ministry of health in 2005 and 2009 for a voluntary agreement signed by various stakeholders like the Food industry and retailers in the covenant. The consumer organisations refused to take part because of its rather soft measures.

Secondly, we see that in Italy schools in particular are targeted in regional policies and stimulated to intervene in the lives of school children, be it with respect tot menus or in other ways. Municipal authorities oversee that school boards take care for healthy menus. Italy is not an exception in Europe with respect to this type of intervention. Also in France give a lots of attention to school menus; every municipal council oversees that primary (and sometimes secondary) schools provide a daily hot meal with three courses. *Menus Scolaires* are published in local newspapers and internet pages of municipalities to show how much care is invested in these important things.

This is not the case in the Netherlands. Although in the Netherlands it is not very common to organise school meals, schools still have considerable influence on eating patterns, for example by organizing what they call a kind of in between at the middle of the morning, mostly around 11:00, which stimulates kids to bring with them chocolate bars, chips and energy dense drinks. Schools also organize for the lunch school milk, thanks to the strong lobby of the milk associations that have a lot to say in what type of milk and how much. Only recently some parents try to change these types of in-betweens and lunches. School and educational organisations are not participating in the covenant, which is striking.

Obesity is managed in correspondence to the two national (institutional) cultures. In Italy obesity is tackled from the input side, in particular the food side and in Netherlands from the output, the movement and exercise side. This is also part of the way the problem of obesity is framed. In both countries cultural heritage does play a role in framing obesity. In the Netherlands there is a strong urge to

Table 12.2 The most striking differences between Italy and Netherlands with respect to obesity and genomics

		Italy	Netherlands
Framing of fundamental concepts	Obesity	Food problem	Health problem
	Food	Pleasure; living for food	Food for living
	Health	Curative	Preventive
	Body	Relaxed, giving eating pleasure	Source of worry
Government		Regional: active	Passive
Industry/retail		Active	Active
Science (genomics)		No science policy	Science policy
Dominant discourse		Politizing and not moralizing	Individualizing and moralizing

see this problem as a medical problem, in Italy with its strong feeling for Italian food as the only good food, the problem is seen as a food problem. Importantly, the emphasis on food is in Italy not done from a moralizing point of view, but from a gastronomical or gustatory point of view: the body is seen as a source of eating pleasure (Counihan, 1999). In the Netherlands the body is seen as to be monitored and controlled.

In both countries it is striking that obese (or overweight) people are not much heard of in formulating policies. In both countries policies don't exist that proactively anticipate upon the possible positive applications of genomics in the struggle over obesity. Genomics scenarios are not held in high esteem. Moreover, both countries lack a differentiated policy, one for the overweight and one for the more severe cases of obesity, that often have very different causes than the simple input and output scheme suggests (Table 12.2).

Conclusion

The comparison has produced interesting differences in the way obesity, the (potential) obese persons and food and health are framed and managed. Not only already existing policy differences play a role here, but also the way social issues are framed, e.g. as a food or health problem, as a disease or not, and as covered by individual, social, familial, school or governmental responsibility. In both countries obesity is tackled from the existing framework that determines the policies in other areas.

In particular interesting is the role of schools. Schools (or educational organizations) are not represented in the Dutch Covenant at all; it seems clear that the Dutch policy has selected only some of the stakeholders of the problem, like industry, advertisement organizations, health organizations and governmental agencies. In Italian policy another selection is made due to a different framing of the fundamental concepts and schools play an important role. In the Netherlands, it is said that a self-regulatory approach to tackle obesity is introduced, but one of the most important players is excluded, and in Italy a rather top down governmental approach

tries to establish with its younger citizens a taste for good food by engaging local authorities.

There are some doubts in how far an output policy (concentrating on the energy loss by movement) as the Dutch covenant is propagating, is indeed effective. One hour of hard bicycling (=600 Calories) equals the consumption of two bananas (Nestle, 2006). As long as the population doesn't want to go back to the fields, the mines, the bleu collar factories and the corresponding hard work, concentrating on the output side doesn't seem very effective. But to have more evidence for this inkling, one needs to do some good comparative research.

Striking is also the expectation that (nutri) genomics will have a more positive embedment in the Netherlands, due to its larger segment of the population that is in favour of a health framing of food than in Italy. The co-evolution of genomics, society and ethics has clearly several trajectories, dependent on tradition and existing social orders and values. We have seen that the comparison results in many similarities but also in differences. However, it is striking that cross-national research into the effectiveness of the different policies of European nations is altogether absent; even the intention to simulate this type of research is absent.

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Part V
Food and Health: Toward a Happy Match of Genomics, Obesity and Values

Chapter 13
Prevention of Obesity and Personalized Nutrition: Public and Private Health

Michiel Korthals

Introduction

As we stated in Chapter 5, two of three main areas of ethical concern connected with nutrigenomics are the relationship between public or social health and nutrition and personalized or individualized health and nutrition and the relation between food and health. Efficacy reasons (Lang and Heasman, 2005, 118) or ethical reasons (UKPHA, 2004) are called upon to support public health policies. It is argued that because of the enormous collective effects, personalized nutrition is not only a personal decision up to the individual, but affects the whole population and even international public health. Should personal responsibility for health be taken into account in setting the agenda for public health, or has collective responsibility a role to play? This question will be discussed in this chapter.

In Chapters 3 and 4 we have distinguished several discourse and constellations, and have elaborated upon the different stakeholders and sectors of society, like agriculture, food, taxation, education and schooling, organization of physical space, that are involved in producing and curing obesity. In Chapter 6 we have discussed several aspects of responsibility and made a distinction between retrospective (who is the main cause) and prospective (who should do what) responsibility. But in all case, structures of responsibility are diffuse. The many horizontal and vertical levels of responsibility are interconnected. In the last chapters of this book we enter upon the question what difference genomics, in particular nutritional or nutri- genomics can make for the management of obesity.

In this chapter we will discuss ethical issues concerning the relationship between social or public health and nutrition strategies versus personalized or individualized health and nutrition strategies and the relation between food and health. In Chapters 14 and 15 we will discuss the ambiguities regarding nutrigenomics.

To tackle this issue, we will first outline some important aspects and assumptions of nutrigenomics. Nutrigenomics can have a function for public health, but

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also for private health, and because of this last function it is often called personalized nutrition. Current designs of nutrigenomics favour the private health option, i.e., personalized genomics. The current structure of nutrigenomics covers *four aspects*: laying bare general relationships between genetic profiles, organisms and environment like food intake and life style; testing and screening of individuals to understand their vulnerabilities; giving personal nutrition advice to individuals or collectives and fourthly, producing innovative food products and services.

Secondly, we will outline the public value of personalized health and nutrition. Finally, I will discuss the relationship between public and private health from a perspective that in literature is mostly mentioned i.e. the utilitarianist perspective of individual autonomy (informed consent or informed choice). However, from a rights based (Kantian) and pragmatist' perspective it seems fruitful also to develop a collective ethical perspective due to the collective consequences of individual choices.

Nutrigenomics as Component of Public Health Programmes

Although nowadays nutrigenomics is often interpreted as personalized nutrition, this was not always the case. In its recent form, nutrigenomics focuses on the value of health in choosing for food, and seems to prejudge an individualizing policy in stead of a public health nutrition policy. Originally, in the eighties of the 20th century, nutrigenomics started with the idea to improve on general diets of the inhabitants of the Western countries. By enhancing the quality of food stuffs like common crops and meat products, the ambition was to raise the quality of public health. It was the time of 'golden rice' and sugar beets without sweets, or, as the article in the TIMES of June 1999 said, guilt free, non-digestible sugar. 'Sweet Taste of Success. Genetic engineers in Holland claim they have finally come up with the holy grail of the food industry: a plant that provide sugar that can make non-fattening and guilt free cakes. Unlike normal sugar beet, whose product is easily digested a new form has been created that can make fructans, sugars, which come in long molecule chains which can make it hard for the body to absorb them'. Even 8 years later, this guiltfree sugar beet still does not exist, so the promise of the engineers was made a bit too early.

Nutrigenomics as Personalised Nutrition

Nevertheless, very soon after the promising start on the level of public health (compare Della Penna, 1999) nutrigenomics made a more individualizing turn toward personalized nutrition, with the idea, that genetic profiles differ very much, and that depending on their genetic profile individual consumers should eat differently. Personalized nutrition has in a certain sense already a long history as part of public health nutrition policies, in particularly during industrialization because of the health condition of the urban labour force. General Practioners made 'food charts' that signalled food deficiencies (lack of minerals and vitamins; Christian

Eijkman and Gerrit Grijns who initiated this, got the Nobelprize in 1928 for the discovery of vitamin B). Diseases were proven to be connected with bad food and undernourishment and good food could cure these diseases.

However, nowadays personalized nutrition (nutrigenomics) is motivated in connection with the *individual prevention*, not with the cure, of food related diseases like diabetes mellitus type 2, hypertension, gallstones, osteoporosis, problems of lipid metabolism, cancer, alcoholism, vitamin deficiencies, overweight and obesity and allergies. Overweight is in particular a case in point that is said to be preventable by individualized nutrition. The personal factors that determine overweight and obesity are seen to be connected with the misbalance between energy-intake and use of energy, like use of saturated fat and sugar, inactivity (computer and television), social-economical factors like urbanisation, educational level of parents and overweight parents, and the lifestyle of parents (WHO, 2005; Friedman, 2004; Roth and Qiang, 2004).

Opening Up the Black Box of Nutrigenomics as Personalized Nutrition

Four Aspects of Personalized Nutrition

The core assumption of personalized nutrition is aiming at, is that food is not anymore seen as positive, having pleasurable features or as neutral, but as having side effects in the sense of disadvantages for human health in the long run (like cardiovascular diseases, obesity, cancer, allergies). The main idea is that people should chose their diet on the basis of their genetic profile and that diet induced diseases, which should be detected as early as possible, should be as much prevented by a change in diet. Some adversaries even propagate a personal food pyramid: MyPyramid (www.mypyramid.gov). First studies confirm that this personal style has some efficacy in addressing people with a health life and food style.

According to Kaput and Rodriguez (2004, 166–177), 'the tenets of nutritional genomics are: (1) common dietary chemicals act on the human genome, either directly or indirectly, to alter gene expression or structure; (2) under certain circumstances and in some individuals, diet can be a serious risk factor for a number of diseases; (3) some diet-regulated genes (and their normal, common variants) are likely to play a role in the onset, incidence, progression, and/or severity of chronic diseases; (4) the degree to which diet influences the balance between healthy and disease states may depend on an individual's genetic makeup; and (5) dietary intervention based on knowledge of nutritional requirement, nutritional status, and genotype (i.e., "individualized nutrition") can be used to prevent, mitigate, or cure chronic disease.'

Partly in accordance with this description, we come to four aspects of nutrigenomics, because we put together the first three 'tenets' of nutritional genomics into one aspect and think it is necessary to add two more aspects that are relevant in particular for genomics focussing on personalized nutrition. The first aspect covers

the complex relationship between the genetic makeup of individuals and their food intake (this aspect can be subdivided in accordance to the three first 'tenets' that Kaput et al. distinguishes in the quotation). Secondly the *screening and testing of an individual* to find out in how far he or she runs any risk. To this aspect belong questions like, how to interpret the chances and how to share this information with your relatives that are possible affected as well. Another question is the privacy of the screening and test results. Thirdly, there is the *personalized advice* to eat in a certain way or broader to live a certain life that this same person gets from some professional. And the fourth aspect covers the *products* (services, foods or drugs) that are the innovatory offspring of nutrigenomics research. These products again can have multiple effects, and it is often unclear in how far these are taken into account. Long term health effects of products are mostly not tested, and therefore not known.

The Institute for the Future has reported in 2003 that 'Nutrigenomics research will increase the understanding of the effects of particular nutrients on specific genes. The efficacy of the science will be determined by the discovery of shared genetic characteristics among subgroups of the population – common population polymorphisms – that occur among fairly sizeable population groups.' (Cain and Schmid, 2003, 3) However it makes clear that not everyone will benefit or wants to benefit form personalized nutrition: 'One third will turn to personalized nutrition' (p. 3).

Personalized Nutrition as a Hype

Many people are interested in testing and self testing for example for cholesterol levels, blood pressure and prostate-specific antigen (PSA) and some producers are eager to jump in to that market niche (BBC-News, 2005). So, there emerge a broad spectrum of at the one end serious testing to at the other end unclear caring apparatuses like massaging apparatuses, face saunas, and self illusion apparatuses. Many ask for self diagnostic tools and apparatuses and it striking that the rather unclear article in one of the main Dutch newspapers *De Telegraaf*, published in the apt time of national food-indulgence (Saturday December 24, 2005) got very quickly 266 reactions (see Chapters 1 and 14 of this book).

Public Health and Personalized Nutrition: Two Aspects

Everyone wants to be healthy, but many of us differ in the view what role health should play in life, what the meaning of health is and also decline to act in healthy ways. What bearing, if any, should our food, health and life choices have on the ethics and policy of food production, food policy, clinical practice and health policy? Should risk-takers have the same claim on scarce resources, such as organs for transplant, as those whose plight is due to no choices of their own? And is there any reason not to impose fees and taxes on risk-takers, be they smokers or mountain

climbers, to defray the added expense of the care they may need? In health resource allocation aimed at reducing the burden of disease, should we regard certain burdens as individual responsibilities: for example, dealing with stigma, or caretaking for family members? What about the uncertainties of nutrigenomics, i.e., that the relationship between genes and their environment is incredible complex to understand, to give meaning and to communicate about? (we will discuss this problem in Chapter 15).

Two aspect of the relationship between public health and personalized nutrition deserve here attention. The first area is the public meaning of the relationship between food and drugs or between nutrition and medicine. The second area is the public value of personalized health and nutrition. In Chapter 14 we will continue this exploration by focussing on one important idea covered by personalised nutrition, the health or gene card. The third one are the increasing ambiguities and uncertainties with respect to fundamental scientific results, and to social and normative dilemmas. This is such an important issue that is deserves more particular attention, and we have dedicated Chapter 15 to this issue. Of course these three aspects interfere with each other; in how far food should be connected with health considerations or even identified with it, is both an issue for collective considerations as a personal affair. The issue of responsibility is also to be considered in these four main areas. But some issues deserve more individualistic concepts, like informed consent and autonomy and protection, and others more collective ethical concerns like trust and justice.

The Public Meaning of the Relationship Between Food and Drugs

The first area covers the relationship between health and food or between drugs and food and addresses the complex of personalized nutrition as a whole. Although there has been always some undisturbing overlap between health and food (see the case of food and herbs in curing diseases), in general the distinction until now has been rather strict. As we have shown in Chapter 5, the most important distinctions between food and drugs are located in the dimensions of personal lives, culture, politics, organizations and market forces. We will repeat them here:

Food is for everyone, drugs only for the diseased;
Food shouldn't have negative effects, because of its life long intake, and drugs sometimes have (acceptable) negative effects because of their temporary intake;
Food choices have multiple reasons and drugs only one (to be cured or protected);
Foods are free available and drugs only on prescription;
Food is not tested on efficacy, but only on safety while drugs are tested on efficacy and efficiency.

If food is indeed becoming medicine in a preventive way, it could be that persons can expect to have side-effects from eating, they are expected to choose their food only on health reasons and they should consult their physicians before eating and have to learn new types of behaviour. All these new activities, expectations, norms and practices imply a redistribution of responsibilities, duties and rights in on the level of legal regulations, political and social agencies and individual practices (Korthals, 2004; Castle, 2003).

Public Value of Personalized Nutrition

The second aspect concerns the issue that even is personalized is encouraged, it is in need of public regulations, that addresses the developments of personalized nutrition in particular, like misuse of information (as in the example on the DNA pill hype), health claims, protection of privacy (input, use and sharing of databases) and personal and social responsibility. Also issues related to communication on personalized services and products such as claims and informed consent need to be discussed. Preparation for optimal consumer protection brings up issues on Intellectual Property and equal access.

As one can conclude from the article on the DNA pill in the Telegraaf (Chapter 1), the notion of personal responsibility for health is vulnerable to intentional manipulation by self-interested (commercially interested) parties and therefore in need of governmental attention

Making Policies in Times of Social and Scientific Uncertainties

This aspect comprises the fundamental and extreme uncertainties one is confronting with in approaching genomics. This has to do with the fact that relationships between diet and genetic profile are sometimes beyond comprehension complex and uncertain (the first level of nutrigenomics, which has the same implications for

the other levels). It is not only that risks galore, like the now established connection between smoking, intake of Vitamin B and increased chance of lung cancer, but also that ambiguities are quite normal, in the senses that two glasses of wine give a higher chance for prevention against breast cancer but a higher chance on cardiovascular diseases. Moreover, many recommendations come from studies limited in duration, subject numbers and types, and dietary variables, which means that they are difficult to interpret and generalize.

The complexity of multifactorial diseases and other interwoven complex causal relations between genetic factors, -omics factors and the environment (life style, social context) confronts ethics with the necessity to transform itself from a 'taken for granted' discipline to a 'searching and experimenting discipline'. We will return to the ethical implications of these uncertainties of genomics in Chapter 15.

Two Ethical Perspectives

With respect to the aspects at hand, we can discern at least two ethical perspectives that are rather common now in medical ethics and can bear some light in the case of nutrigenomics oriented towards personalized nutrition. The first one emphasizes the protection of consumer/citizens by viewing all ethical issues from the point of informed consent or informed choice, i.e. from the point of the individual freedom and autonomy that seeks to make boundaries against social powers that threaten to transgress the boundaries of privacy and of private freedom. Although issues of justice, i.e. the social fair distribution of resources play a role here, the idea is primarily that social powers should be limited in their grip upon individual consumers. Patients and consumers should be enabled to protect themselves against powers that invade their personal responsibility by giving them rights (Chadwick, 2004).

In the alternative model, the emphasis is on coordination and interaction between consumers, producers and other stakeholders, which means that individual consent and choice can play a role, but in a social context of interaction and social learning, and of distributing responsibilities according to issues and needs. Consultations and deliberations with stakeholders (as a matter of fact including consumers) to find agreement and disagreements play an important role here. The prior aim is not to protect patients and consumers against professional powers; patients and consumers are invited and stimulated to take part in consultations and are given the opportunity to tell their narratives, interests and anxieties.

In both models, the concept of autonomy plays a pivotal role, however in the first as individual autonomy and the second as social or collective autonomy. As the German philosopher Immanuel Kant (1724–1804) is the foremost thinker of autonomy it is worth while to spell out some of the implications of the concept of autonomy. Kant argues:

'Laziness and cowardice are the reasons why such a large part of humanity, even long after nature has liberated it from foreign control (naturaliter maiorennes), is still happy to remain infantile during its entire life, making it so easy for others to act as its keeper. It is so easy to be infantile. If I have a book that is wisdom for me,

a therapist or preacher who serves as my conscience, *a doctor who prescribes my diet*, then I do not need to worry about these myself. I do not need to think, as long as I am willing to pay.' (Immanuel Kant, *Was ist Aufklärung*, 1785, in Kant, 1949) (my italics)

As food choices are included in ones autonomy, consumers should determine their own food (diet); as a consequence, the food markets and food professionals should follow and they should act as our keeper. Only paying for your food, without performing according to your autonomy, is a sign of infantility, or, as it says in German translated in English, having no say over your mouth. Autonomy is not only covering what goes out of the mouth but also what goes into the mouth.

Kant gives some more and interesting clues on what 'autonomous food choice' means in his *Anthropology from Pragmatic Point of View* (1798/1790; 1949). In general, he puts humans between Nature and Reason. Man has neither only capacities from nature nor capacities from reason but from both, where Nature stands for passions and sensual experience and Reason for transcending nature by using the reasoning faculty in knowing, willing and appreciating (judging). For instance, enjoying art and food socially, means transcending nature by assessing something that is given and subsequently structured according to the judgmental structure that you share with other rational beings. This type of (communicative) assessing is what autonomy means, so autonomy has nothing to do with informed consent or choosing or doing what you want.

The main idea of this publication is, to reason upon the circumstance what human beings can make from their nature (Kant, 1949, 450). Human beings are involved in a development towards standing on their own feet, although hesitating and stumbling. Taste has according to Kant the extraordinary feature that it stimulates solidarity in enjoying. Enjoying food refers to culture and society. But there is more. A good meal enjoyed during a long time with good people is a occasion where experience and reason is the united and which can be repeated again and again. Through having common meals, reason acts upon the affects, because they stimulate solidarity and humanity.

One could even here use the concept deceit of reason, because through good meals reason gives occasion to more solidarity and humanity by 'clothing virtue in a positive dress'. Meals are a stimulus to come together and share your thoughts with other rational beings. Kant takes into account we do not have the same taste for food: some like this and others like that. However, he introduces the concept of comparative universality to make clear that on closer inspection, by experiencing and talking, many of our tastes overlap. Comparative universality is a term that refers to the narrative overlapping of our food preferences. It stands for both that the taste is personal, which you have recognize in the food and that tastes have some commonality, proven by the fact that we enjoy the meal together. (Kant, 1949, 567).

Concluding, for Kant food and meal contribute essentially to informal ties of community, due to their multifunctionality. In the words of Georg Simmel: 'Eating and drinking, the oldest and intellectually most negligible functions, can form a tie, often the only one, among very heterogeneous persons and groups.'

Of the two alternative models, the second one of social autonomy is directly linked to Kant's ethics. The first concept of individual autonomy (and protection) is

more connected to Utilitarianism, which emphasises individual utility and happiness as the most important criterion for the outcome of ethical decisions. The concept of personal autonomy lies at the heart of the utilitarian doctrine of for example John Stuart Mill (1806–1873):

The only freedom which deserves the name, is that of pursuing our own good in our own way, so long as we do not attempt to deprive others of theirs, or impede their efforts to obtain it. Each is the proper guardian of his own health, whether bodily, or mental or spiritual. (John Stuart Mill, On Liberty, 1859, 1975).

As long as one can do what one thinks is in favour of ones own health and as long as one doesn't harm others, then actions are ethically seen allowed. Harm towards others is the category that marks the distinction between personal autonomy and social life, and harm is the mean indicator that ethically seen something goes wrong. This means that individuals first and foremost should be protected from the harmful actions of others or should be enabled to protect themselves from those harmful actions. Kant however thinks more positively about the relation between individual and social, in terms of enrichment and humanisation and not in terms of harm. With these two models in mind we can now tackle the three main areas of ethical concern with respect to nutrigenomics.

Several potential approaches to develop interventions, based on genetic or genomic research can be thought of: (1) identification of high-risk groups based on family history (2) identification of relevant pathways based on pharmacogenomics or (3) identification of relevant interventions through nutrigenomics. If genetics/genomics would be able to better tailor prevention advice, so that either compliance or effectiveness of interventions became higher, a successful contribution to fight the epidemic can be imagined.

Discussion of the Two Aspects of the Relationship of Public and Personalized Strategies

The Relationship Between Food and Health

People have a complex set of considerations why they choose the food they do, which are different from the considerations that determine their use of drugs. There are at least four factors determine our food preferences in general: genetic factors, social and cultural factors, bodily history and personal historical factors.[1] The *genetic factors,* building up the genetic make up, are generally not changeable; they determine taste in general (like bitter and sweet) and partially taste-development. The *social and cultural factors* consist of determining organisation forms and values, like family relationships and health or nationalistic values. The *bodily history* influences tongue and mouth, but also nose and ear, which are part and parcel of food

[1]Korsmeyer, 2002; Korsmeyer doesn't take into account the personal history of tasting in listing factors that determine food preferences, p. 82, 98.

choices. When one is tasting food, one is also tasting ones own body, not merely as a matter of fact. Finally the *personal historical factors,* like the family history and how it is internalized. Moreover, in actually having a meal additional factors do play a role as well, like the present conditions of the meal, the present condition of the body and the actual pleasure and displeasure in tasting. Gustatory taste and food choice are strongly intentional and cognitive: it matters what one eats and to know what one eats. They comprise the visual, the smell (olfactory), tongue senses (gustatory), and the auditive (e.g., crunchy or not). The fact that taste is cognitive, means also that taste can be learned, and can develop in a certain direction. A yellowish substance with a rotting smell turns suddenly into a delicious cheese upon tasting it, preferable with nice and knowledgeable people.

More generally, in the domains of food and health culture, politics, science and society, the most important distinctions between food and drugs cover that food is for everyone, drugs only for the diseased; that food shouldn't have negative effects, because of its life long intake, and drugs sometimes have (acceptable) negative effects because of their temporary intake; that food choices are motivated by multiple reasons (see above) and drugs by only one (to be cured or protected); that food are free available and drugs only on prescription available, and that food is not tested on efficacy, but only on safety.

From an ethical point of view, objections against the identification of food and medicine can be heard, like that food should not be seen as medicine and that society is not a hospital, meaning that health should not be the all determining value in food choices. For instance, Crawford (1980) is warning for the medicalisation of every day. When just as in medicinal ethics, the doctor-patient relationships becomes central, so in food ethics the producer consumer relationship in the same terms are becoming central, we will encounter the same narrowing perspective. As an acute observer notices: 'For some decades the doctor-patient relationship has been the central concern of medical ethics. This focus has marginalized public health issues by concentrating on individual patients and individual practitioners, and thereby on one aspect of medical structures in the richer parts of the world.' (O'Neill, 2002, 150). The English Food Ethics Council views the exclusive orientation on health in food choices as a transformation of society into a hospital (FEC, 2005) which is in the case of prevention of obesity not desirable and not necessary, because physical activity is a good recommendation as well (Hillsdon et al., 2004. Petrini (2002), the founder of Slowfood, and a fierce defender of the social and cultural aspects of enjoying food, quotes approvingly Madame Sevigny, 'Health is enjoying the other enjoyments. When the other enjoyments are taken away, we live longer, but we lose our health.'

The largest promise on genomics is made in relationship to prevention: identifying the pathways that bring the individual in a state of 'predisease' would ease the delay of the disease, because they can be influenced by specific food intake. However, there is an interesting phenomenon here that makes this type of reasoning rather flawed: the prevention paradox. In 1985, Sir Geoffrey Rose identified this paradox that stipulates to the differences between high risk individuals and risk populations (Rose, 1985). The two categories, remedies for high risk individuals and remedies for risk populations do not necessarily coincide. For a successful risk population strategy, it is mostly not effective to concentrate on the high-risk individuals;

on the contrary, due to the fact that mostly only a small minority has a high risk that is even not recommendable.

However, because of the development of the food sciences, traditional truths on healthy food collapse: for instance, wine, chocolate, vegetable oils, and milk chance their health value. Food intake should correspond with changes in life styles: What to eat in the new situation of sedentary work and other changing social contexts? We are facing now two new grey zones: food as medicine and drugs as enhancements and we can not eliminate them. This means that there is some to reconsider the relationship between food and medicine; the refusal to review the traditional distinction between food and medicine looks like sheer dogmatism. Even with Kant in hand one could argue this: because there is a difference between obeying a physician and taking into account the advice of experts on food. Moreover, the Eurobarometer (2005) shows that the association of food with health is in EU only made by one person in five; the idea that society transform into a hospital is not very realistic. As long as health remains one of the considerations in food choice and supply, and the multiple functions of food stay in place, there is some reason to reconsider the intricate relationship between the two (Korthals, 2004). When personal nutrition on a modest scale is implemented, there the first area of ethical concern can be overcome, can be our final assessment. This opens room for reflection on the new gray zones between food and health when personalized nutrition on a modest scale is implemented in certain areas. This reflection can start by analysing the second and third main areas of ethical concern. Table 5.1 has to be supplemented with a double third row (food as drugs and drugs for non-patients; Table 13.1).

Second aspect: the relationship between personal and public health food policies

Table 13.1 New grey zones between food and drugs

	Food	Drugs	Grey Zone: food as drugs & drugs for non-patients (modafinil, Ritalin), enhancement drugs
1. Side effects	Not accepted	accepted	??
2. General?	In principle	patient groups	Quasi patients
3. Choice	Multiple reasons	Health reasons	Health, enhancement
4. Time taken	All life	During illnesses	Preventive against susceptibilities
5. Delivery	Free available	Over the counter	Both
6. Testing	Only safety, not efficacy	Safety and efficacy	?
7. Production	Food companies, farmers, (open production systems)	Drugs companies: Closed lab	Mixed Drugs in Greenhouses/ Pharmadrugs
8. Responsibility	Governments and food sector	Physicians, drugs companies, governments	??
9. Trust	Sector not highly trusted	Sector trusted	?

According to many food scientist and food industrialist, personalized nutrition and its concomitant vehicles like gene passport, comprising the results of screening and testing, are means of individual empowerment and should replace public health nutrition policies (German and Watzke, 2004; Koelen and Lindström, 2005). Moreover, insurances companies and many governments are of the opinion that consumers should take more responsibility for their health and not rely too much upon governmental health regulations. They are arguing: 'you're responsible to do what is healthy' and call this self control and autonomy (see the paper of the UK Department of Health, 2004, *Choosing Health*, issued by the Blair government 1997–2007).

However, some food companies are rather hesitantly entering the market of personalized nutrition. In an adjacent branch, that of personalized medicine, which is already more developed, it is very often the case that personalized medicines aren't commercially viable. Personalized medicine means that companies will have to be satisfied with only a (small) share of the market and don't cover all the (potential) patients. As a result, few new Pharmacogenomics drugs are filed for license in the USA. According to the FDA White Paper, the number of new drugs and biological applications submitted to FDA has declined significantly. Moreover, the UK based Public Health Association (2005) argues in her reaction to the Blair Government paper, *Choosing Health or losing health*? that public health should be the main target for governmental policies. This association argues that in the long run the poorer parts of the population and health will lose in a health and food system where individual responsibility is the main organizing principle (Darnton-Hill, 2004). In the same vein, Lang tries in *Food Wars* (2005) also to make a strong case for the primacy of public versus individualized health nutrition politics. 'Targeting whole populations provide governments with better chances of public health success, whereas targeting "at risk" individual could be socially divisive. This does not mean, as is sometimes assumed, everyone eating the same or a bland diet, but moving overall dietary behaviour *en masse* in a healthier direction.' (Lang and Heasman, 2005, 110). But in the end he concedes that 'individual tendencies' (idem, 120) do have to play a role in a public health system.

Moreover, from an ethical point of view, one could argue with Kant that personalized nutrition in the sense of a gene passport or chart means disempowerment and not enrichment of social autonomy, because one makes oneself dependent on a physician. Only as a social autonomous member of a rational community, personalized nutrition is something to give a try and the issue boils down to the balanced relationship between the autonomy and solidarity, not an either or (compare Castle et al., 2006). This means that the current and future existing genomics research agendas must not forget to include a substantial component of genomics directed research towards public health (Khoury and Mensah, 2005) and other functions of food like taste (El-Sohemy, 2007; see also Chapter 15).

Concluding, there are some reasons in favour of personalized nutrition, as long as it does not push public health nutrition aside; it needs therefore governmental regulation also in this respect. Also, from a utilitarian standpoint, there is place for personalized nutrition, as long as unhealthy lifestyle costs too much and individual responsibility can bear the costs.

Public Regulation of Personalized Nutrition

Granted that indeed there is a role to play for personalized nutrition oriented towards health, we are faced with particular ethical issues in connection with the scientific peculiarities of nutrigenomics, in particular the huge complexities of the interactions between genome, genetic profiles and environments, like diets and life styles. This fundamental complexity reduces severely the possibility of reproducing experiments in other locations, because food and life styles differ so much and are difficult to exclude (Sinha, 2005; Tate and Goldstein, 2004). It means that validation and falsification of scientific relationships are confronted with extreme difficult and expensive research designs. Genomics is not about a single relationship between one single gene and its expression, but about the reactive genome, contextualizing on all levels. Food has multiple effects on the genetic profile, and is dependent on the food choices that again are influenced by life style factors. One implication is that there is a good chance for fake claims and unrealistic expectations, of which the consumers have to be (made) aware.

The implication of the uncertain and multiple effects of food on the body and genetic profiles is that for consumers and regulators not risks but uncertainties and ambiguities galore! With nutrigenomics we do not live in the risk society but in the uncertainty society. As we have seen, the complex relationship between food and genetic profile allows for various reactions of the body on food, sometimes positive, sometimes negative. Genes influence the expression of other genes in proteins and the organism and vice versa, so the genome is not one, stable, all determining commando post. Moreover, traditional truths on healthy foodstuffs, like wine, chocolate, vegetable oils and milk, collapse. For some wine is healthy, for some not; first all vegetable oils were seen as healthy, later not, etc. Still, we need serious research, i.e. validated results of nutrigenomics for fine-tuning food in lifestyles, although it will be difficult, because of these uncertainties and ambiguities, to incorporate the aspirations and result of nutrigenomics in our daily life, in adequate policy measures and in ethical acceptable research agendas.

Future Prospects

Genomics' application to reduce the phenomenon of obesity has still an uncertain future, and a lot depends on the interaction of research developments, research priorities, prospects for profits and ethical concerns. On the one hand it is unmistakably the case that a more personal appeal to customers of food and medicine to incorporate recent health standards into their food styles can have some effect. From this perspective, it seems ethical desirable that consumers learn to cope with the hypes, the uncertainties and relative certainties of this new approach. This implies not only room for informed choice, but also for consultations and deliberations on these uncertainties. On the other hand, complementary, from a public health point of view, the potentialities of nutrigenomics in improving the health of the population, in particular of the least well off, should be developed as well.

Conclusion

We discussed in this Chapter 2 aspects the relationship between public and personalized health and food strategies. The first is that of the relationship between food and medicine. Although there are good reasons to be careful and to make this distinction, there is room for taking into account new connections between food and medicine, a grey zone that is in need of regulation and requires additional attention of consumers and producers. Attention is in particular needed that health doesn't socially and personally function as the only motive behind food choices, and health policies should not stimulate in that direction. Secondly, the issue of the relation of public health versus personalized nutrition requires a balance between solidarity and individual autonomy. In Western European societies, one is motivated to look for such a balance, and only processes of broad and continuous consultation and deliberation can find out what this implies. However, finding these balances must not forget to stimulate also genomics research directed towards public health.

Thirdly, we addressed the regulation of personalized nutrition in particular, which requires that consumers are able to cope with uncertainties in identifying and selecting their main vulnerabilities and able to incorporate these in their narrative life plans. Moreover, this has various implications for governments, scientists and industrialists. The two main ethical models at hand, the individualized and the social autonomous models give different answers to the three main areas of ethical concerns.

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Chapter 14
Expectations and Disappointments of the Human Genome: The Genomics Health Card and Anti Obesity Pills

Michiel Korthals

Introduction: A Short History of the Genome

Knowledge of the human genome has great potential for human health. It may help us understand the origins of diseases and tackle these more precisely by using medicines that work at DNA level. This has also for the nutritional sciences great potential. For decades now epidemiologists have tried to find links between health and food. Research at genome level may help to reveal the relation between these two. It could track the origins of diseases and help prevent them. It may also prove the healthy influence of nutrients. However, this potential is overshadowed by the enormous complexities surrounding the genome and the possible applications of genomics and nutrigenomics.

DNA was thought to be the 'language of God' – according to President Clinton – and the blueprint of the human body, concealing the secrets of life. If this blueprint would be uncovered we would 'know' for certain. We would be able to solve the mysteries of our bodies and prevent many fatal diseases (for example: Smith, 2005; Stephenson, 2008). However, once most of the human genome had been sequenced after the year 2000, this idea collapsed. The workings of the human genome and its interaction with the environment, like: nutrients are complex. This became clear after only 22,000 genes had been identified. Interactions between genes, enormous numbers of genes reacting to one nutrient and opposing reactions of genes triggered by the same nutrient make the challenges posed by nutrigenomics overwhelming (Piatigorsky, 2007). Besides the fact that it is rather difficult to test the health effect of nutrients and therefore certain diets and products, it also turns out that, on the genetic level, it is hard to determine the boundary between illness and health. Nutrients have to interact during a certain period in which the body does not yet give any signals of illness at that specific stage (Miller, 2004). Research on the influence of diets on health results often in incoherent or even contradicting evidence. It is no wonder that some food scientists express their scepticism about the

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scientific basis of health claims: '. . .the Food and Drug Administration's oversight over health claims has eroded, and the United States now allows `qualified health claims' for which there is hardly any evidence, as long as a disclaimer is included.' (Katan, 2004, 181).

With respect to obesity, the results have as yet (2009) been quite meagre. More and more genes are found that influence satiety, overweight, obesity and its implicated vulnerabilities, and besides lots of complexities no clear-cut 'fat' genes have as yet been found (Shell, 2002). Hofker and Wijmenga (2009) states: 'At present, the observed genetic variation for obesity explains only 1% of the total genetic variation expected to be present in the population.' A full list of genes and their functions coding for a plurigenetic or multifactorial vulnerability such as obesity, where so many organisms play a role (food, human body, bacteria, etc.), will probably take years and years to make, if at all feasible. More in general, several candidate anti obesity pills were launched, but they didn't survive the usual governmentally organized approval procedures (see the last section).

Besides the complexities and uncertainties of the experimental nutrigenomics results, the interaction of nutrigenomics with society is largely unknown. How will professional groups, like dieticians, supermarkets, general practitioners, respond to the development of nutrigenomics, its complexity and uncertainties? How will they influence its application? Will the projected end-users be able to integrate nutrigenomics products and services, whatever they may be, in their daily lives? (More about these topics in Chapter 15).

This short history of nutrigenomics shows a rise and fall in expectations and taken for granted certainties (for similar cycles see Brown, 2003). The development of the science presents a dynamic in which 'organized scepticism' (Merton, 1968) follows 'organized utopianism' (our wording, MK): truths and certainties taken for granted are destroyed or better, are unmasked as (un)truths and uncertainties. The persistent intellectual dispute among competing research teams in which established truths fall prey to critical scrutiny is an indication of becoming mature with respect to the scientific understanding of the world. Scientists claim the right to make promises *and* mistakes; that is the core of scientific ethos (Merton, 1968; Kuhn, 1962; Pinch, 2000).

This oscillating history shows that during the period of emerging paradigms or disciplines scientists are in need of an organizing utopian idea that rallies their energy and directs their attention. Organized utopianism, so: promises, seems necessary and will give occasion to mistakes and false promises, but organized scepticism will unmask them later. The history of science is full of these, later discovered, mistakes, which in some cases can turn out to be big problems or even catastrophes. Examples of serious mistakes made in agriculture and food sciences are the use of lead, radioactivity, and DDT, plus the claim that all vegetable oils are regarded as healthy (Bryson, 2003, chapters 7 and 10).

An Example: The Emergence and Demise of the Genomics Health Card

The genomics health card (mentioned in Chapter 5) can be considered as a good example of the exciting development of scientific utopias. The idea was first publicly introduced in the Netherlands in Wim Kayzer's quite influential television program, 'Better than God', broadcasted by the Dutch Public Channel *VPRO* Nederland 3, 1987–1988, in its second part, titled 'Good is only the Best' ('Goed is alleen het beste', 85 min). In this part, in a discussion with an ethicist, several questions were dealt with, like: what will be the social and ethical implications of a possible identification of an individual's genetic constitution through a simple blood proof and of putting these genes on a card with not only the deviations that are already known and effective, but also other deviations, potential or to be expected? What will this mean for insurance companies, and will an increased number of companies require genetic screening of their employers? What will be the implications of storing these data on gene cards in data banks? This idea of a gene card or gene passport became popular and at conferences and in interviews many experts and stakeholders referred to it. The president of the board of Wageningen University and Research Centre, Prof. dr. A. Dijkhuizen (2003), even stated that the health card would enable us to provide food recommendations to individuals on the basis of their individual gene profile: 'Maybe thanks to modern information technology, will it become a real card on which all the valuable advises are collected.' B. van Ommen, one of the leading scientists of the Nutrigenomics consortium (NUGO) invented the slogan: 'every eater the right snack' ('elke eter de juiste hap', van Ommen, 2001). Professor W. Saris, a famous Maastricht University food scientist prophesied in 2001: '[. . .T]hrough personal DNA cards one can very detailed identify what the vulnerabilities of someone are.'

What happened with genomics in general, also happened with the health card: first the scientists came with the expectations, promises and even utopias, then the journalists followed (Bubela and Caulfield, 2004)

Only in 2003, as one of the first, The Guardian published the article: 'First it was smart drugs. Now it's smart diets. Bruce Gierson on what your genes want you to eat' (The Guardian, May 2003). A similar type of article appeared in the New York Times, May 2003: 'what your genes want you to eat: A trip to the diet doc, circa 2013. You prick your finger, draw a little blood and send it, with $100, to a consumer genomics lab in California. There, it's passed through a mass spectrometer for protein analysis and cross-referenced to your DNA profile. A few days later, you get an email message with your recommended diet for the next 4 weeks. It doesn't look too bad: lots of salmon, spinach, selenium supplements, bread with olive oil.'

But the euphoria slowly vanishes: after a few years, the idea of a health card lost its attraction. Around 2003/2004 it became clear that the idea meets insurmountable obstacles. More careful voices are heard, like that of Sir Paul Nurse, head of the English Royal Society 'Science in Society' project, Nobel Prize winner for 2001,

and head of Cancer Research UK (Williams, 2003). In more sophisticated journals and reports, like the Human Genetic Commission Report, studies appear on ethical alternatives regarding existing practices of screening and the storage of genetic information as well as genetic counselling.

And then other experts warn explicitly against the gene or health card, like Dr. Muin Khoury, director of the Office of Genomics and Disease Prevention at the US Centers for Disease Control, who states: 'Don't Rush Into Gene-Based Diets', 'Right now, no one in their right mind would offer genetic testing' (in: Bruce Grierson, The Guardian May 15, 2003).

In the beginning of 2005 an expert seminar was organized at *Universiteit Utrecht* with the title Genetically Tailor-made Diets. The results of this seminar were clear: individualized genetic advice may in the very long term be feasible, but most probably will not enable to create health advantages. The same tenor can be found in the very carefully worded text of the National Center for Minority Health and Health Disparities (NCHMHD) of the American National Health Institute of Nutrigenomics (www.UCDavis.edu).

At a conference of the Scientific American, titled: Targeted Medicine, held in New York on November 11, 2004 (www.targetedmed.com), only sceptical remarks were made about the person-bound gene or health card, e.g. by Toby White, CEO of Celera, and by Mike Svinte, CEO of IBM Health. Their doubts about personalized medicine – in a financial sense, the bigger sister of personalized food – are: it shrinks the market, because selling drugs for a very small niche of a population offers less than for a larger one. For specific groups it could bring back onto the market drugs that have been disapproved of by the FDA. It could also divide the market into different types of consumers which would be confusing, but would also reduce opportunities on the market. White argued: 'Instead of describing it as the first step in a journey of a million miles it was described as a destination and I think everyone was done a disservice by not clarifying that' (The Guardian, November 18, 2004). But not everyone is a sceptic, and some utopians are still around, like Guy Miller, CEO of Galileo Laboratories Inc. (cited by Fogg-Johnson, 2004): '. . .new opportunities will emerge to deliver to consumers, whose genetic susceptibility to specific diets and diseases are known, products tailored to individual dietary needs.'

New Target: Groups?

Due to these considerations, it seems to be the case that a more sophisticated program is developed, that focuses not on individuals but on vulnerable groups (Penders, 2008). As a matter of fact the main obstacle here is the classification of people (patients, consumers) into groups with different genetic profiles. According to what criteria should this classification be made? Should one use as a standard purely genetic or lifestyle factors, or a combination of both? From an industrial point of view it seems more viable to choose for this trajectory of group profiling. Consequently, individuals will not be classified on the basis of their personal DNA, but on the basis of their belonging to a certain group that can be identified by the

fact that its members share a certain genetic profile and a certain life and food style of which it is established that this combination makes them vulnerable for prediseases. It could be that the persons own loyalty to a certain group does not match with his or her genetic group profile. Moreover, this approach raises the problems of genetic discrimination and exclusion. It could also give rise to new types of group consultation, to built trust between the researchers and other professionals and the group members.

However, not all the arguments critical of or opposing the health card can be met by this move, in particular arguments regarding its commercial viability and the possibility of discrimination of these groups.

Disillusion?

According to the Gartner Group, an advisory company in the field of new technologies, smart cards go in the direction of the 'trough of disillusionment', as you can see in the accompanying figure (Fig. 14.1).

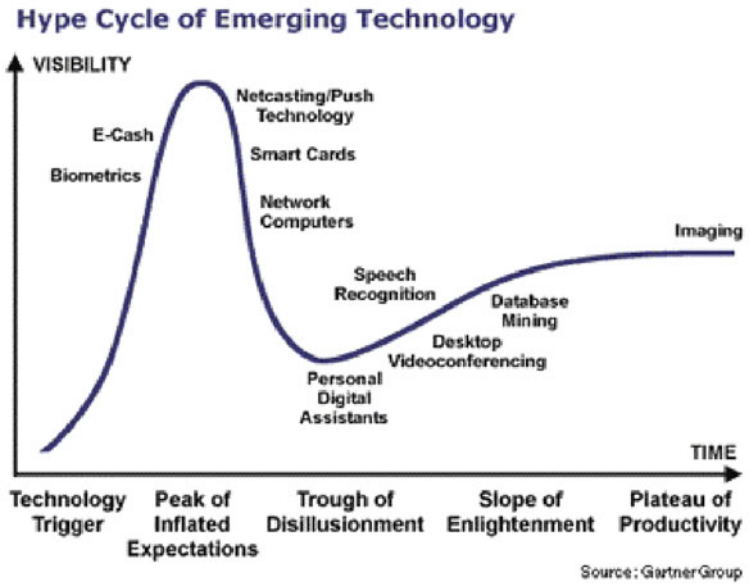

Fig. 14.1 The 'hype cycle of emerging technology'

In so far as the gene or health card belongs to the category of other 'smart' cards the future isn't very bright. It could be that certain aspects of the health card have some value and will survive, but which ones?

It often happens that science and technologies are driven forward by promises, expectations and even utopias that in the end are not carried through. In a science

and technology dependent society this continued disillusionment could finally create a kind of distrust of any expectations and promises made, in particular when these promises are made in periods of lobbying for funds.

We could be nearing the point of satiety of badly founded promises and expectations, and science and technology will then lose its anchor point in citizen behaviour and trust, in particular when other utopias seem to be more realistic. Which of these will reach the Peak of Inflated Expectations and survive the down- fall into the Trough of Disillusionment?

The Rise and Fall of Anti Obesity Pills

The history of anti obesity pills shows a more or less similar pattern, with the difference that the downfall has come faster and governmental regulation does play a considerable role. In May 1996 the British Medical Journal made public that the United States Food and Drug Administration had announced that it had approved the first new obesity pill (Redux) in 20 years (Barnett, 1996). In a year-long clinical trial of 900 patients taking dexfenfluramine in disjunction with a reduced-calorie diet, 21% lost at least 15% of their initial total weight, according to Wyeht-Ayerst'. However, after it was shown that this pill had severe side-effects (pulmonary and heart affections), its approval was withdrawn by the FDA. On the internet however it is still advertised as approved and can be bought freely.

Another example is Sibutramine, the drug that first was seen to be the better substitute of Redux, of which the story is told in Chapter 8. This pill got the FDA approval in December 1997. It treats obesity, both in attaining and in maintaining weight loss. Although the drug still has its approval status, it is very controversial. Wikipedia reports:

> Studies are ongoing into reports of sudden death, heart failure, renal failure and gastrointestinal problems. Despite a petition by Ralph Nader-founded NGO Public Citizen, the FDA made no attempts to withdraw the drug, but was part of a Senate hearing in 2005. Similarly, Dr. David Graham, FDA "whistleblower", testified before a Senate Finance Committee hearing that sibutramine may be more dangerous than the conditions it is used for.
>
> A large randomized-controlled study with 10,742 patients (SCOUT) examined whether or not sibutramine administered within a weight management program reduces the risk for cardiovascular complications in people at high risk for heart disease and concluded that "Six-week treatment with sibutramine appears to be efficacious, tolerable and safe in this high-risk population for whom sibutramine is usually contraindicated."(. . .)
>
> On December 22, 2008, the Food and Drug Administration issued an alert to consumers naming 27 different products marketed as "dietary supplements" for weight loss, that illegally contain undisclosed amounts of sibutramine. In March 2009, Dieter Müller et al. published a study of sibutramine poisoning cases from similar Chinese "herbal supplements" sold in Europe,

containing as much as twice the dosage of the legally licensed drug. (http://en.wikipedia.org/wiki/Sibutramine)

A third example is Rimonabant, which got provisional approval of the EU in 2007, but only half a year later was withdrawn because of severe side effects (e.g. depression). However, newspapers wrote very enthusiastic stories about this new pill, and the *NRC-Handelsblad*, a Dutch quality newspaper even dedicated its entire news magazine to it in January 2006. Other newspapers followed (Volkskrant, HP/de Tijd); and later that year they were accused of providing only one-sided information, as they didn't report on the negative effects already familiar at the time.

The eagerness to introduce something into the market that has not been very well tested, and is known to have severe side effects and can be bought without any kind of consultation, makes it clear that there are very strong interests in producing anti obesity pills. As is clear from this short report, journalists don't stick to high standards where reporting all the pros and cons of a case is concerned. They are often dictated by interests totally different from the truth.

Conclusion

In the short history of (nutri-)genomics it is striking that some of the most appealing ideas, like that of the health or gene passport and the anti obesity pills, already existed. The idea of these existing devices, expected to get a new shape with the emergence of the then new science, genomics, inspired many. However, the connection between these devices and the promises of nutrigenomics did not match. The health card or the various anti obesity pills for persons who run the risk of becoming obese is still very, very far away and possibly not the best objective to strive for. The media and the reciprocal career system of scientists, research managers and journalists often play a considerable role in pushing immature or even unsafe scientific devices onto the market. The responsibility of its bearers to act on the basis of these presumably valid devices can be disputed due to the fact that they have not been scientifically proven. Individuals are overburdened by quite controversial services and products and can not be expected to bear the responsibility of diminishing their burden of vulnerabilities. The balance between social and individual regulation should be better regulated by more public health measures than thru these individualized means.

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Chapter 15
Matching Nutrigenomics, Society and Values

Michiel Korthals

Introduction: Ambiguities, Framing and Co-evolution

In the course of this book we stumbled upon so many ambiguities, controversies and uncertainties of the relationship between obesity, genomics and society that the time has come to try to find out their ethical meaning, in particular with respect to the improvement of the co-evolution of genomics and society. In discussing the current state of treatment of obesity, we found in Chapter 3 that there are at least three different ways of framing the problem of obesity: a Behaviour (individualizing and moralizing), an Environment (politicising and not individualizing) and a Body (individualizing but not moralizing) discourse. What will happen when genomics enters this field? Will genomics stimulate more the first, second or third discourse? What will this imply for the relationship between health and food; will food indeed be seen as an instrument of health or as a drug? Will the (potential) obese consumer of nutrigenomics be framed according to the vocabulary of one of these discourses? What type of responsibilities (Chapter 6) will be social acceptable?

With respect to the future of genomics, we outlined in Chapter 7 three scenarios: first *Health as merit* (individual oriented and foreseeing diagnostics); secondly C*orporate responsibility* (environment oriented and foreseeing no cure) and thirdly, *Liberation of fun* (body oriented with diagnosis and cure). Which scenario will assist in tackling the main problems and solve the struggle over responsibilities? Which one will survive? Will genomics produce a cure and a diagnosis or only provide some clues for certain extreme cases of obesity? The subsequent chapters were devoted to the problems with respect to genetic testing and how genomics can blur the distinction between health and disease and between a medical and an aesthetic perspective. In Chapter 8 we outlined the 'script' behind current genetic testing, covering a genetic deterministic message and assuming that the consumer of those tests could be seen as an 'information

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empowered consumer'. In Chapter 10 we concluded that only part of the Dutch and Italian social institutions and food and life styles are attracted by the current genomics innovation strategy. In Chapter 13 we argued from a philosophical point of view that the current script and configuration of the consumer are seriously flawed; seen from a sophisticated theory of autonomy like that of Kant, this script is more about immaturity and enslaving than about empowerment of consumers.

We showed that the development of nutrigenomics is not free from ups and downs of steering ideas like the health card and an anti obesity pill (Chapter 14). Moreover, in recent literature the intrinsic uncertainties of the relations between genes and their environment are a hot topic, in particular the fact that genes can have multifunctional features. The classical idea of one gene-one protein (Beadle and Tatum, 1941) is now abandoned and genes encode a variety of transcripts and proteins (Pearson, 2006). Genes can have different functions in interaction with their environment (Piatigorsky, 2007). They code for proteins that can have different, even opposing functions. The phenomenon of moon lighting, gene-splicing, or gene-sharing allow proteins to function in distinct modes and makes the road from genotype to phenotype and back more complex than ever (Sriram et al., 2005). We cannot know for certain how far it ever will be known what the benign or harmful effects of nutrients, foods, or even diets will be. Finally, many effects, tested on European populations, may not be generalized to other populations (Ng et al., 2009; Easton et al., 2007). It could be that the methodological shortcomings of many gene-environment studies are so severe that scientists, who are not conscious of these problems, can nearly prove everything about causal relationships between a gene, some diet and obesity (Katan, 2010, mkatan.nl).

All these ambiguities are multi actor problems, which are moreover multi networked into other problems. In this chapter we will delve deeper into the ethical meaning of all these scripts, vicissitudes, hypes and trends without however draw conclusions about 'what to do', i.e. about the responsibilities. We summarize the inherent normative character of technologies and their normative influence on our moral vocabularies, strategies, attitudes and institutions. In the next chapter we will outline the implications of the current state of nutrigenomics for responsibilities. Henceforth, we will firstly review the main ambiguities of the genomics scenarios and what they imply. Then we will discuss two important approaches of these ambiguities and argue that they do not sufficiently take into account the normative role of technologies and innovations, in particular their role in initiating new moral vocabularies (and attitudes). Finally we will develop the idea of co-evolution and fair representation and discuss how the initiating role of technologies with respect to new vocabularies can be democratized.

In the table below are listed the partners interacting in the co-evolution of genomics, society and values; next to the vicissitudes and ambiguities of genomics per se, are the social order and its treatment practices of obesity, the responsibilities (and their practices) and the shifting values and norms. They all interact and the main question is than, do they match in a happy way? (Table 15.1).

Table 15.1 Co-evolution in general of genomics, social order and values

Genomics	Obesity and social order	Responsibilities	Norms and values
Gene-environment	Behaviour Environment Body	Genetic responsibility	Life and food styles

Vicissitudes Determine the Concepts and Vocabularies About Obesity and Genomics

Roughly, the ambiguities and uncertainties can be discerned with respect to the present state of genomics and obesity and its future. They concern the current conceptualizations (or scripts) of health, food, body, and responsibilities with respect to their management, the role of governments and markets parties and the developments of science and technologies.

All these discussed ambiguities and uncertainties are not new, but more or less endemic to a science based society, a society in which co-evolution or co-production of science and society shape the societal dynamics. These issues can not be tackled by science alone, and scientists should not exaggerate their role by pretending that they can answer them. On the other hand, society should not expect answers for them from science. Co-evolution implies that both developments, that of science and that of society develop and simultaneously influence each other. How they influence each other, and how these developmental lines can positively and socially acceptable stimulate each other, will be the subject of this chapter.

The framing or conceptualizations of those leading concepts determine the analysis of the problem of obesity and the solutions that are seen as feasible. In our discussion of the comparison between Italy and Netherlands these different conceptualizations and their implications for solutions and policies became very clear (Chapter 12).

Existing vocabularies are incorporated in attitudes, manners, institutions and established technologies; when new technologies arrive, even in their infancy, these existing vocabularies are forced to react, because they are challenged and can only survive when they adapt but also because these new technologies incorporate new moral vocabularies and stir new moral debates with new participants. The acceptance of a new technology requires that the potential conflicts between the two types or moral vocabularies are made liveable: either the first gives in or changes its vocabulary, or the second gives in and changes accordingly. Or, a third possibility: the technology and the existing vocabularies learn from each other and result in something totally new, which can be called a ‘happy match’ between genomics, society and ethics. Anyhow, the more invasive regarding peoples life and concepts the new technology is, the larger the social and moral changes and controversies. Vocabularies or scripts are not dead concepts, but located in the messy conditions of real lives and relationships and appeal to consent or dissent. As we have seen, the

different scenarios or scripts of the combination of strategies to manage obesity and of genomics assume normative concepts about for instance health, food, the body, and consumers' life styles. It is these concepts that determine what we do and assess as a right action, but they may be not themselves actions; they are ways of framing actions and opinions.

In another publication (Keulartz et al., 2004) we have contrasted this relation between different vocabularies with relations between arguments and particular courses of action and combined the four possibilities with different types of ethical orientation.

However, the connections between technologies, their assumed moral vocabularies and their potential clash with or absorption by existing moral vocabularies, can not hide the fact that they are immersed in ambiguities and uncertainties.

Applied Ethics, Technology Assessment and the Vicissitudes of Genomics

Applied Ethics

In several chapters we discussed the strong and weak points the applied ethics approach, mostly inspired by medical problems. The strong points are the systematic elaboration of concepts like informed consent and autonomy. Both concept put pressure on the innovators and suppliers of services and products to take heed of the consent of the consumers on the basis of delivering honest and integer information.

The weak points are exactly the emphasis on giving information and the neglect of a process of searching, finding out the meaning of the innovation and participating in the innovation. The systematic neglect of processes, dynamics and ambiguities and the emphasis on an agreement, a product, make these concepts acting like a traffic light. Either one is in favour and gives ones consent, or one is against and refuses to give ones consent.

The concept of informed choice is not a fruitful concept in a dynamic and ambiguous context, due to the fact that it does not say anything about selecting the more certain and less certain recommendations and the incorporation of well-established health considerations into one's diet and personal health. What consumers, citizens and all concerned need are ethical categories that assist them in identifying problems, making these selections, i.e. need categories of consultation and deliberation, and learning processes in which all concerned can bring in their life stories (narrative input) and can be assisted to become robust vis-à-vis the health and food problems that they are confronted with.

Technology Assessment

Technology assessment concentrates on the process of a technological development and its social effects (Est and Brom, 2010). It originates in the sixties of the 20th century when it became clear that technological developments produce both

positive and negative consequences. In particular the side effects of technologies, like that of the use of pesticides on bird life and more generally bio-diversity (Rachel Carson) and safety of cars (Ralph Nader), made scientists aware it would pay out to pay attention to potential benefits and losses of a new technology. In the sixties the research field of technology assessment started in the US with a governmental agency and other countries followed. It is now widely seen as the task of technology assessment to identify and analyze these consequences and to assess the development in a stage as early as possible, because then the context of innovation can take measures to limit negative effects. Later in the eighties and nineties TA broadened its scope to cover also the design of technologies and to try to incorporate measures that steer the technology it self. Interactive (Grin et al., 2004), deliberative and constructive (Rip et al., 1995) technology assessment schemes emerged that both analyzed and created public debates between lay public, scientific experts and policy makers in a democratic way (Hamlett, 2003). National governments started democratic debates in cases where strong dissent about a technology, like Genetic Modification, was rampant. In an analysis of these forms of TA, Driessen and I (Driessen and Korthals, forthcoming) conclude: 'Ethical analysis in this approach implies mapping short and mid term social effects, leaving aside long term and wider societal ethical interaction of conglomerates of technologies with existing moral vocabularies and attitudes.'

The two approaches mirror each other in the evasion of the core question: what are the internal ethical assumptions of genomics trajectories and what are their societal repercussions, in particular with respect to moral norms, concepts and strategies? We conclude that these two approaches do not consider the ambiguities and uncertainties of science-society networks and neglect the steering, often concealed, role of innovations with respect to the framing of moral vocabularies, even in the early phases of innovation. Innovations do not simply have social effects, but have also moral effects in facilitating or even partly creating new moral vocabularies and new moral discourses. Ethical assessment of the social effects of innovations, as is done in regular technology assessment often neglects the fact that in the course of the development of certain innovatory trajectories, the corresponding moral norms originally used as standards also change; this makes the assessment exercises often out-of-date when the innovations are in their later phases. Many of these ethical assessments have therefore a conservative outlook. To contribute to a more beneficial co-evolution of genomics and society it is therefore advisable to take into account the full range of events that is affected by the dynamics of this interaction.

Dealing with Framing Vocabularies and Ambiguities in Deliberative Learning Processes

In Table 15.2, the second row concerns ethical management of vocabularies, in its product form or in its process form, and in this last case as a learning process. It is exactly this terminology of 'vocabulary' that enables to analyse the co-evolution of genomics, society and ethical norms and values in a way that does not block the two

Table 15.2 Product and process with respect to ethical perspectives on particular actions and vocabularies

	Product	Process
Context of justification	Arguments and justifications for or against courses of action	Structuring and safeguarding fair public deliberation and decision making
Context of discovery	Dramatic rehearsal Criticizing and renewing vocabularies, exploring possible future worlds	Conflict management Aiding an open confrontation of heterogeneous moral

developmental pathways but indeed stimulates them positively and in a beneficial way and that does not stumble upon the ambiguities and uncertainties.

To makes this clear, a short detour to the pragmatist origin of a philosophy that is emphasizing the moral impregnation of technologies, their uncertainty and the way society can live with these features. The pragmatist philosopher Charles Sanders Peirce started his enquiry in modern science by accepting the fact that science is aiming at making absolute truths uncertain. He coined the concept 'fallibilism' later embraced by philosopher of science Karl Popper. Peirce starts with the 'scientific community' that can in the long run correct mistakes and find new exploratory ways to overcome barriers and ambiguities. According to Peirce, we live in a non-deterministic world, which implies that uncertainties and ambiguities 'determine' our actions and their interactions with other worldly events. He attacks all determinist philosophers who think that there is one worldly structure and that science should try to lay bare this structure: 'there are three things to which we can never hope to attain by reasoning, namely, absolute certainty, absolute exactitude, absolute universality' (Buchler, 1955, 56).

Pierce does argue the same kind of fallibilism for ethics: 'The doctrine of fallibilism will also be denied by those who fear its consequences for science, for religion, and for morality.' (p. 58). Fallibilism does however not imply that scientists or people stop looking for an answer what to do, and should doubt everything: 'Let us not pretend to doubt in philosophy what we do not doubt in our hearts.' (p. 229). A radical doubt is not necessary, even a mistake. 'All human affairs rest on probabilities [. . .]. If man were immortal he could be perfectly sure of seeing the day when everything in which he had trusted should betray his trust, and, in short, of coming eventually to hopeless misery. He would break down, at last, as every great fortune, as every dynasty, as every civilization does. In place of this we have death' (p. 162) '. . . death makes the number of our risks, of our inferences, finite, and so makes their mean result uncertain.' (p. 162) However, because we are social beings, and science and ethics as social processes as well, we can have hope that a satisfying answer to our problems can be found: '. . .there is nothing in the facts to forbid our having a *hope,* or calm and cheerful wish, that the community may last beyond any assignable date.' (p. 163).

John Dewey, inspired by Peirce's ideas, has developed several strategies to deal with ambiguities. Dewey recommends not conquering them, but living with them and viewing them as opportunities for learning. I quote here from a larger study on these strategies (Korthals and Komduur, 2009):

> First, he (Dewey) recommends looking for a *selection of uncertainties* that we should pay attention to by identifying and selecting important, unbearable ones in contrast to less relevant, bearable, ones. Procedures like consultations, deliberations, and exchange of stories and life narratives. (. . .) Secondly, it is ethically desirable to explore the uncertainties, paradoxes and various scenarios in *debates* that are organized on the basis of the idea of inclusion: 'The course of history is nothing but the story of men's struggles from one generation to generation to find the more and more inclusive order. *Invent some manner* of realizing your own ideals which also satisfy the alien demands, that and that only is the path of peace!' (James, 1897, 205). (. . .) Thirdly, to strike the balance between the social and the personal level, one should also pay attention to Dewey's idea of 'happy with uncertainties.'

Public learning processes dealing with ambiguities and uncertainties should be organized because they enable to raise all relevant viewpoints and interests and to criticize them from all sides. In particular in deliberative learning processes concerning paradoxes, ambiguities and uncertainties, dissent should be the general debate mechanism, not consent. Scenarios do play a role in stirring the debate. John Dewey called those deliberations 'dramatic rehearsals' (Keulartz et al., 2004; McVea, 2007).

Towards a Happy Match Between Nutrigenomics, Society and Values

Nutrigenomics in applying to obesity has in one way or another to listen to (potential) obese persons. In the chapters until now there is a lot of writing about (potential) obese persons but now it is time to include them in our reasoning. It is time to suggest some social devices, how this listening to (potential) obese persons can be organized in the field of genomics. Just as with respect to the population at large, so with respect to potential obese persons, life and food styles differ according to the five we have earlier distinguished (see Chapter 10). When such important ways of realizing the ideal life vary that much, it becomes a key ethical issue in this plural landscape how these styles can positively co-evolve with scientific and technological innovations in the field; possibly both food styles and technological innovations can learn from each other to eliminate mistaken assumptions and improve strong points. I have introduced the concept of 'fair representation of food styles' in innovation processes from a liberal ethical framework, in which individuals have the right to choose freely a life- and foodstyle, as long as it does not harm the public interest and in which food styles are stimulated to flourish and improve themselves, under the same condition.

Pitkin (1976) defines representation as: 'involves treating something as present which is "nevertheless not present literally or in fact"'. The 'something' covers in her book the various opinions of citizen consumers on political issues, like power

distribution, responsibilities and other public issues. Mostly, in democracies at least, do citizens have a voice, but because of all kinds of reasons and constraints they are not present in the decision making process. Instead, they decide to let others speak for them, and act and decide on behalf of them. So, citizens have a voice and the right to delegate this voice to their representatives and the right to hold their representatives accountable.

Fair representation of food styles is not directly connected with these political issues, but with making present in the food chains and innovations networks the voices of different food styles. It covers production and availability of food products and everything connected with it, like information, labelling, marketing, public debates, and public regulations, in markets (industry, farming, communication, information etc) and research. The absence of representation would mean that food styles do not have a voice in the innovation process and the match between genomics vocabularies and scripts and societal ones will not be a happy one. Because food is an important aspect of social and cultural identities, individuals and groups deeply appreciate their food choices (and implicitly or explicitly the production processes) and are very often unwilling to change their eating habits.

Nutrigenomics and Fair Representation of Foodstyles

What is the implication of the concept of fair representation of life- and foodstyles for nutrigenomics and its approach to the problem of obesity? According to this concept food science and food research should pay as much attention to research for food as health as for food as taste and the varying food concepts of food styles. Nutrigenomics in its prominent and present shape, in short, should broaden its conception of (healthy) food towards a concept of good food, which requires a reorientation of the current research agenda towards the foodstyles currently present.

The incoherencies between the concepts on food and health of genomics innovations and those of society are best tackled by taking into account a fair representation of foodstyles and the positive synchronization of the co-evolution process between science and society. Research managers should organize the research agenda of nutrigenomics in a representative way, not exclusively oriented towards personalized nutrition, but oriented towards the prevention of common illnesses, common conditions and chronic diseases and toward non-health values of food. The main research policy aim in nutrition should be the encouragement of the (in)formal ties by pleasurable eating that has as one among other conditions the improvement of health. Given the plurality of foodstyles of (potential) obese persons, health should be a secondary goal in eating and consumer groups should be empowered as stakeholders. By taking into account the different concepts of health and food, nutrigenomics researchers can formulate more social acceptable research priorities. The full complexities of health can even better be incorporated by organising end user panels in the different genomics research trajectories.

With respect to the recommendations that nutrigenomics scientists or other professionals feel necessary to produce regarding food intake, the concept of fair

representation gets another twist. Often these professionals forget that their competences and knowledge do only cover one aspect of that quite complex field. Monsen et al. argue (1991): 'The scientist, who is convinced that diet and health are related and that changing diet patterns will benefit health, even though this relationship has not been conclusively proven, faces an ethical dilemma. The principle of beneficence requires making the strongest, most convincing presentation of this perspective when speaking to the public. However, treating people as capable of making their own choices requires the nutrition scientist to provide the public with arguments of other experts who interpret differently the current scientific knowledge or the public health implications of that knowledge.' The concept of fair representation implies in this case of food intake recommendations a strategy of respect for autonomy of consumers regarding their food choices and indeed urges to choose for the second strategy. An implication of this concept is that it seems advisable to let recommendations of food based on nutrigenomics be accompanied by social research of their applicability.

More generally, the treatment of (potential) obese persons can only be ethical acceptable when they are informed about the limits of the treatment. This is even recommendable in the case of the quite elaborate approach that is proposed by Albano et al. (2008). This approach covers the whole life stories of an obese person, including producing and processing food.

Thirdly, the concept of fair representation can also have a fruitful application with respect to products, like functional foods, in particular with respect to the claims that are connected with them and the way they are communicated to the (various) publics. Seen for example from a traditional food style, a claim about healthy effects of a food item has a different meaning than seen from a fast food style.

Conclusion

The ambiguities and uncertainties regarding the genomics approach to obesity includes competing discourses of the treatment of obesity, the choice between different futures with respect to genomics, in particular the possibility that no cure at all will emerge, the intrinsic scientific uncertainties of genomics and the often undecidable choice between different concepts of health, food, disease and responsibilities.

These vicissitudes and ethical concerns and consideration presented here are often tackled by applied ethics and technology assessment approaches, that however, either (in the first case) are not considering the fact that ethical norms can change under the influence of the assessed innovation or (in the second case) that these innovations give rise to ethical intuitions and insights towards new moral frameworks that enable users to co-evolve with the innovations.

In this chapter it is argued that a happy match between genomics, society and ethics taking into account these vicissitudes can be best tackled by deliberative learning processes, in which the concept of fair representation with respect to life and food styles plays a dominant role. As we have seen, these learning processes

are inspired by the interaction between the procedural perspective emphasizing the necessity of consultative and participatory organizational relationships in the new grey zones between medicine and food, and the substantive perspective that both cherishes individual autonomy and embeds it in socio-cultural contexts.

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Part VI
Conclusion

Chapter 16
Conclusion: Beyond Genomics and Obesity

Michiel Korthals

Genes are time bombs. They explode in due time thanks to certain diets

(Dr. B. van Ommen, director of NUGO)

This crème protects your DNA; it stimulates the rejuvenation of your skin cells.

(Nivea DNAge Zone Action, body lotion and hand lotion)

Introduction

In this final chapter, first the main points will be summarized of this investigation into the relationship between genomics, society and obesity. We have seen that although obesity is a serious problem, it is also a much contested one, even with respect to the definition, the more so with respect to its diagnosis and treatment. Subsequently, the main ethical issues will be identified that emerge when genomics researchers do concentrate on obesity. We will delineate our main conclusions with respect to the shifting responsibilities in the broad field of stakeholders and the changes in the attribution of meaning that health and food are subjected to. Many aspects of genomics are ambiguous in a very fundamental sense; genomics researchers and professionals produce ambivalent results. The two quotations above illustrate this quite nicely: on the one hand it is said that our genes are like explosives running the risk of going off and are therefore dangerous, on the other it is stated that we have to protect our DNA. For the end-user of genomics these ambivalences will create new ethical challenges for which we will provide some comments.

Genomics Going Obese: From Promises to Practices

We started our study on genomics by focussing on the relationship between genomics and obesity because the last is seen by many as a severe contemporary epidemic, attracting increased attention of governments, the industry and public

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health organizations. Accordingly, the World Health Organisation (WHO, 2003) found in one of the largest research projects it had ever undertaken, that 60% of world deaths are 'clearly related to changes in dietary patterns and increased consumption of processed fatty, salty and sugar foods.' Obesity is a multifaceted vulnerability: it can have many (simultaneously working) causes, most therapies fail, and a lot of political and commercial interests are connected with obesity maintenance, diagnostics and therapies.

Our initial assumption in Chapter 1 was that genomics could make a difference. Initially, with the emergence of Genomics, many scientists regarded the discovery of the mutated BRCA genes as the beginning of the solution to the breast cancer problem. And indeed some researchers claimed to have found obesity genes and anti obesity pills (Barnett, 1996; however, most pills were later disapproved of by FDA, see Chapter 14). But the development took a different turn, and, like breast cancer, genes turned out to be much more varied, difficult and diverse to decode and to decipher. Moreover, many scientists are now reluctant to agree to the fact that genetic clues can guide medical practices (Marshall, 2003).

In the beginning of the 20th century scientists slowly realized that with genomics a new holistic approach would be necessary which, in principle, abandons the old adagio of one gene for one feature (Beadle and Tatum, 1941). Genes do interact with each other, with other proteins and enzymes, with the organism and the wider environment. Along cellular pathways, different types of expression of a gene are even possible depending on the characteristics of the receptors, mutations and polymorphisms and so on. A different food intake can influence the expression of genes and determine the metabolisms and the whole organism. The cellular nods, the cellular and intercellular pathways all play a role in obesity, but nobody knows in what measure. The sequencing, screening and mapping of proteins of 'healthy' and 'unhealthy' pathways now and then provide promising results, but nothing more than that.

During our research into the implications of genomics for the study of obesity, our team was continuously confronted with new information and apparently new trends. In contrast to the usual, ethical approach to science and technology, we have explicitly addressed these changes and the concomitant uncertainties and the complexities of genomics, and not assumed a fixed, consensual image of the nutrigenomics science. Nutrigenomics is here defined as the research that uses knowledge of the genome to prevent diseases or to improve health by means of food, and is even more complex than genomics itself, because it also has to take into account non-human organisms involved in food intake and digestion – like bacteria and viruses. These complexities affect the ambiguities linked with the different applications of nutrigenomics. In the scenarios *Health as Merit* and *Corporate Responsibility* we took into account that genomics might not produce any cure at all.

We started with the idea that knowledge of the human genome had great potential for human health and that it would help understand the origins of diseases and tackle these more precisely by using medicine that would work at the DNA level. Also for the nutritional sciences it would have immense opportunities. For decades epidemiologists have tried to find links between health and food. Research

at genome level could help reveal the relation between food and health. It could find the origins of diseases and help prevent them. It could prove the healthy influence of nutrients. However, this potential is overshadowed by the enormous complexities encompassing the genome and the possible applications of genomics.

DNA was thought to be the blueprint of our human body. If this blueprint could be uncovered we would 'know'. We would be able to solve the mysteries of our bodies and cancer would be according to President Clinton for our children a word that only refers to a stellar constellation. However, after most of the human genome had been sequenced in the year 2000, this idea collapsed. It started with the steady decrease in estimates of human genes; while in 1989 it was estimated that humans have appromixately140,000 genes, in 1990 the estimate was 100,000, in 2000 there were 40,000 left, which decreased to 36,000 in 2002 and later, in 2005, to 22,500 genes.

Secondly, the direct results of genomics have been rather meagre: in a 2005 survey in the British Medical Journal, the 87 biotech medicines approved by the European Medicine Evaluation Agency from its inception in 1995–2003, when the European pharmaceutical law was revised, were re-assessed. The assessment concludes: 'In conclusion, the promises of biotechnology substances to be more effective and less toxic than conventional drugs have been only partially fulfilled. Many of the substances produced so far are analogues of existing drugs and have contributed little to innovation in medicine (Joppi et al., 2005)'. The New York Times states in 'Awaiting the Genome Payoff' (June15, 2010): 'That "genome bubble" has long since popped'. Famous and notorious companies like Sciona that specialized in personalized nutrition and testing went broke.

The complexity of genomics research and its implications for technological applications are also stressed by many scientific overviews. In a large survey of scientific developments, Frank Desiere, after informing on the developments in the various omics fields and in the research into gut processes, like the role of bacteria, concludes: 'Clearly, we have barely begun to scratch the surface of understanding how the nutrient compounds within natural food interact within our biologic systems.' (Desiere, 2004, 75)

Moreover, epigenetic research became more and more important: the role of hereditary factors that are not transported by genes, but by the environment, like the pressures in the womb on the foetus which may even affect later generations, as is the basic idea of epigenetics. So the stay in the mothers' and grandmothers' wombs has turned out to be much more important than expected. They conclude that a tough time in the uterus and unhealthy food choices can damage the child in many ways. Moreover, research into obesity started new pathways, and promising research into gut bacteria, viruses and their genetics. The same message on complexity is to be read in the paper on obesity and gut bacteria by Bajzer and Seeley (2006): 'But a great deal remains poorly understood' (1010; compare Nature editorial, 2006; Check, 2007; ENCODE Project Consortium, 2007.

The connection between food and genomics has also turned out to be extremely complex. One aspect that one should not forget is people's sensitivity to food images, and the individual variations in sensitivity. As Beaver et al. (2006) report

in their paper 'Individual Differences in Reward Drive Predict Neural Responses to Images of Food' some are more prone to switch to chocolate when seeing images of chocolate than others: 'Our findings demonstrate that there is considerable personality-linked variability in the neural response to food cues in healthy participants and provide an important insight into the neurobiological factors underlying vulnerability to certain eating problems (e.g., hyperphagic obesity).'

Furthermore, personalized nutrition came under fire, not only from social and ethical, but also from commercial and scientific points of view.

With respect to interventions meant to reduce obesity, the changes are also striking. The studies which show that dieting doesn't help, and in many cases even aggravates the problem, abound. Many now echo that changes in lifestyle are necessary, but in what way and how they don't tell. Moreover, who wants to change his or her whole lifestyle? Isn't the idea of an incremental lifestyle a much better idea? (Devlin and Zhu, 2001) Besides, it is rather difficult to test the health effect of nutrients and therefore of certain diets and products on people's health simply because it is hard to determine the line between illness and health (see Chapter 8). Nutrients have to interact during a stage in which the body at that specific moment in time does not yet give off any signals of illness so is in pre-symptomatic stage.

In the three scenarios that we have developed, we included considerations of these uncertainties. We respectively emphasized individual responsibility (Health as Merit), the environmental context (Corporate Responsibility) and the body (Liberation of Fun). The scenarios made the co-evolution of science and ethics visible. Because it is dependent on varying ethical assumptions, genomics can take a different trajectory.

Ethical Issues

Next, we analyzed the main ethical problems with respect to the connection between genomics and obesity.

Firstly, ethical issues are first and foremost the many distribution or justice related problems, like the concern in how far the various parties will benefit, some more than others? Is the balance of benefits and losses unequally and unjustly distributed and will poor people bear the main burden? Are there any chances of genomics being abused? Who decides on the directions genomics are to take? Will experts decide or politicians, or the industry?

Secondly, there are many normative issues like the framing of concepts in vocabularies and scripts, for instance that of obesity as an illness, a syndrome or an inconvenient constellation or that of test, assuming that health determined by genetic profiles (Chapter 8). These vocabularies or scripts determine subsequent courses of action and normative ways how one should see health, food and one self. Other normative issues are: what values and strategies are to be incorporated in the genomics of 2015 (of: in genomics in 2015): will it be a strategy for the enhancement of individual life in the West? Will it try to eliminate socially wide-spread diseases? Will

genomics develop cures to compensate obesogenic behaviour? What values will genomics radiate to its wider contexts in the future?

Connected with the identification and range of values and strategies incorporated and radiated by genomics, there are two problems related to the value of health vis-à-vis that of food and of beauty and pleasure. The first one is that health is indeed an important value, but not an all- encompassing one. The pleasure of living a good life is probably more important in staying healthy than the continuous and conscious orientation on health as the only directive value. The emphasis on the value of health can become so dominant that other aspects and values of human life diminish in importance. The second problem is the issue of the definition of health and its various implications: what does this term cover and what not; what should it cover, are multiple definitions possible and does everyone in the end has the right to choose the definition they like? Does one have a right to sport an 'unhealthy' lifestyle? What is the relation between health and food? We have discussed these issues in Chapter 13.

Thirdly, another ethical complex covers the ethic-political dimension of public versus private: in policies as well as in the attribution of responsibility. As we have seen in the three scenarios described, they particularly differ in how far the balance tips towards either the individual or the collective (Chapter 7). The scenarios also differ in public health versus personalized or private health policies (see Chapter 13); the balance between public versus private is important as well in regulating the procedures of testing (Chapter 8).

Fourthly, one of the many scientific and ethical ambiguities with respect to genomics is the possible outcome of useful products and services. Although lots of optimistic stories have been produced and many people have expected products and services to soar, nothing much has been happening in this field so far (Chapter 14). The FDA (2004) even complained about a coming stagnation: 'During the last several years, the number of new drug and biologic applications submitted to FDA has declined significantly: the number of innovative medical device applications has also decreased. The costs of product development have soared over the last decade.' Moreover, the European Food Safety Agency (EFSA) has rejected 80% of the 1000 health claims that are filed by companies, of which, as a matter of fact, not all based on nutrigenomics (EFSA has still a 3000 to scrutinize; Science, 2010). Nevertheless, the most extreme possibility is that genomics will not produce any diagnostic or device that has curative implications, which corresponds with scenarios one and two (see Chapter 15).

Besides the complexities and ambiguities within the science of nutrigenomics, also its interaction with society is incoherent, complex and fragmented. How will companies and end-users react to the developments of nutrigenomics, its complexities and ambivalences? How will they influence its applications? Nutrigenomics is thus impregnated by internal and external ambiguities and uncertainties. Research on the interaction of genes and the environment has revealed that many human diseases have both genetic and environmental components. Even traditionally 'environmental' diseases, such as infections, appear to interact with genetic components in the human host. Environmental and nutrigenomics research (in combination,

ecogenomics) will inevitably increase the understanding of individual susceptibilities to toxic exposures in the environment and any harmful side effects of medication; therefore it shows great promise for the improvement of the prevention and treatment of human diseases. However, to realize the benefits of this research requires careful attention being paid to the ethical issues that are particularly relevant in this context and to the social contexts in which the innovations are embedded: a happy match between the three is still far away.

Genomics and Obesity: Shifting Responsibilities

Genomics, in stressing the interaction of genes with proteins and with the environment, may create new responsibilities and fresh ethical problems. For the individual it may create unbearable responsibilities, e.g. genetic responsibility, for society it may create a genomics divide -between the poor and the rich- and a genomic way of living eliminating ways of living that emphasize non genetic factors. These alternatives presuppose different ethical positions, like rights and autonomy, justice and fairness and (non-utilitarian) values. The decision-making process in connection with these technological alternatives is an ethical issue as well: who decides what type of technology is used for whom and according to what procedures and approach?

To unpack the blaming games, we turned to philosophies of responsibility in Chapter 6. First we discussed the causal theory that stresses the causal connection between an event and an actor in delineating responsibility; subsequently we analyzed the theory of role responsibility, which stresses the guideline of not doing any harm by performing your job according to the best practice, as fixed in the past. So, both theories are negative -avoiding harm- and retro-active. Also, we discussed the theory of public responsibility, which reacts to new developments in socially and ethically acceptable ways, even when there are no clear best practices. So it is both positive and prospective. On the basis of this theory we have answered the question what responsibility means, i.e. its content and scope. While role theory stresses the being liable or even punishable for risks and dangers, public or pragmatist responsibility theory concentrates on future acts that enhance trust in the professions vis-à-vis the public. Responsibility is not only an issue that is generated by quasi-causal links between intentions and activities, as the causal and role theory presuppose, but also between knowledge and action. It means that informing the public and stimulating its opinion formation on knowledge and values is also a feature of a profession. This conception of responsibility doesn't imply that if someone is held responsible, he or she is not per implication to be blamed or to admit that something went wrong. It points into the direction of being accountable and taking care of, not of being blamed. So the blaming game should be shifted to a discourse on responsibilities for problem complexity management and coping in an ethically acceptable way. To hold someone accountable because he or she knows something is not the same as blaming someone, but it is meant to find out how to improve similar situations.

The complicated problems in confused contexts, so characteristic for obesity, like the issue of the many hands, and that of diffusion of responsibility have been discussed. In those contexts, denial and disavowal of responsibilities often happen. Genomics creates new public responsibilities and new distributions of responsibility, but also new types of responsibilities for food professionals. So it will shift the locus from individual responsibility, as indicated in the first constellation body, to the other types of responsibilities and other forms of autonomy mentioned.

We have shown that the three types of responsibility very neatly correspond with the three types of obesity constellations. It is not that we like the magic formula of three so much, but it is the result of our inquiry into the different constellations, scenarios and theories of responsibility. We here make a distinction between two possibilities. First the possibility that genomics provides a great understanding and insight into obesity, but not really an effective diagnosis or even cure: the first two scenarios. In this case, the three types of responsibility do not change accordingly. The second possibility is the reverse of the first, suppose that genomics will indeed produce a successful diagnosis and moreover a promising cure: the third scenario, it would then be possible for the three different types of obesity constellation to imply changes with respect to their corresponding notions of responsibility. However, we must also recognize the possibility that, indeed, genomics will not produce any results, and that the social situation remains the same before and after the, scientifically successful, introduction of genomics: a kind of zero scenario (Table 16.1).

Table 16.1 Different types of responsibility according to the three obesity constellations before and after the (successful) introduction of genomics

Main discourse/counter discourse	Behaviour/beautiful	Environment/victim	Body/ill
Before genomics	Causal responsibility	Role responsibility	Causal responsibility
After genomics	Role/ Genetic responsibility	Diffused/ Role responsibility	Diffused/Role/ Genetic responsibility

We have introduced a new term, *genetic responsibility*, to cover the idea that, according to the individualizing scenarios, people will be held responsible for coping with their genetic outfit. Genetic responsibility in this sense doesn't have the rather common meaning (Etchegary, 2009) of accepting one's own genetic profile and in particular one's influence with respect to offspring and relatives. But it refers to the use of one's manoeuvring space in diminishing as much as possible the harmful effects one's vulnerabilities may have on society. According to this concept, one does not behave according to one's genetic responsibility once one knows one has an increased genetic risk of obesity, but one exposes oneself intentionally to all kinds of, unhealthy, food impulses.

Genomics creates fresh opportunities and eliminates others. Due to its emphasis on gene-environment interactions, there is no reason for holding the individual personally responsible. So, it deviates from the first constellation although it stresses

the importance of lifestyles: one that emphasizes behaviour, a second that has social contexts as its core, and a third that centres on the body.

Trends, Hypes, Expectations and Ambivalences of Nutrigenomics

In Chapters 14 and 15 we have shown that the technological trajectory of genomics belongs to an innovation network continuously producing expectations and promises alternating with disappointments and inconsistencies. We have also discussed the hazards and risks, the unknowns, incoherencies and fundamental ambiguities of nutrigenomics. It is rather difficult to test the health effects of nutrients and therefore certain diets and products on people's health as it is hard to determine the line between illness and health (see Chapters 8, 9, and 13). Nutrients interact during a stage in which the body at that moment in time does not yet show any signs of illness. The influence of nutrients on health and on genetic make-up of humans is not coherent: not always either positive or negative because both effects may emerge in different ways.

If the current trend keeps on moving toward more privatization of life sciences research, innovation and development, new social and political conflicts will arise on the ensuing divide between actors and countries in possession of these opportunities and those not able to afford them. This will give rise to new kinds of tensions, because these inequalities clearly are contrary to the principles of justice and equality. When exclusive representation of one life- and food style is pushed forward in innovation trajectories, than the feeling of unfair representation will become dominant and an unhappy match results.

Besides these complexities and uncertainties within the science of nutrigenomics per se, it cannot yet be decided how nutrigenomics may co-evolve with society and ethics. Health care professionals do complain about a lack of knowledge and skills to be able to give their patients apt advice. Since 2006 direct-to-consumer services have a bad reputation and these companies now appear to be in decline after a short period of growth.

Paradoxes of the Current Co-evolution of Nutrigenomics, Society and Values

The central ethical issue of (nutri) genomics is how to feed and medicate oneself in a technological culture. With regard to food and drugs, consumers are not merely passively undergoing certain innovatory changes. The consumer of genomics services and products is not only the one who consumes, but also the one who buys and prepares and forms opinions on the products he or she consumes and on the corresponding production processes, as witnessed by the recently emerged concept of consumer concerns. The current vocabularies and scripts of the various aspects of the nutrigenomics innovation trajectory suggests concepts and strategies that do

not really match with societal regulations and ethical values citizen-consumers have with respect food, health and their body. We will now outline the four types of paradoxes of this 'unhappy match' between genomics, society and ethics in the field of individualization, prevention, risks and ambiguities, and information

In this context, the first paradox of individualization of (nutri-) genomics gets its shape: tailoring food to individual preferences to tackle obesity means huge collective implications, for example: the acceptance or non-acceptance of certain health characteristics of your offspring and of the genetic heritage you inherited in general (see scenario one). *The first paradox is: individualization is also a new type of collectivization*. Individualization certainly doesn't imply that there are no social consequences of these individualizing practices or that socially upheld regulations are superfluous, on the contrary. First, suppose, a person has asked for genetic testing: this person has his genome and most of its SNPs in common with others, our relatives. Genetic diagnosing of one person is of direct importance to this person's relatives. What is one to tell the others about diagnostic results and who will communicate these, and how to counsel these persons? are some of the main questions that emerge and they have immediate collective implications. Moreover, these individualizing acts of being genetically diagnosed and counselled, on the basis of informed consent, presuppose social contexts in which these acts have been coordinated and regulated. Regulation for example is necessary because too many providers of tests do not comply with the most simple and minimal levels of decency: they simply cheat their customers in their greed to earn money by only decoding a minor part of the relevant genes. Sciona is accused by many of selling tests and drugs on the basis of nothing much. The social component or context of individual consent doesn't imply that informed consent is to be gotten rid of or that some kind of collective consent is necessary, as contrary to individual consent. It only implies that one should try social procedures to find out how to live with these paradoxical, collective implications of individualization.

The *second paradox* is that prevention on the basis of genomics implies that more than ever, the living present has become the focus of concerns coming from the past (the genomic heritage) and the future (the risks foreseen). Past and future collapse in the present and they are able to shatter the present (see also Mayer-Schönberger, 2009). The same, differently stated: the individuals who are constantly worrying about their future risks and doing their utmost best to prevent them, when taking into account their past, from their own actions to those of their ancestors, lose sight of the day-to-day concerns confronting them and run the risk of losing contact with life. Moreover, there is one certain risk that will always confront these worrying people and will appear to them in all shapes possible: death, in whatever disguise, will ultimately destroy all living beings. If obesity is no longer the number one killer, some other disease or risk will definitely turn up as the next number one. *The second paradox is: prevention leads to aggravation and medicalisation.*

Medicalisation gets a particular twist in the case of genomics and the prevention of possible risks. In the early seventies of the previous century, it was implied that physicians had taken over and that everywhere citizens had become patients.

Nowadays, it suggests more of a kind of 'proto-professionalization': the internalization of professional attitudes towards one's own body and acting as a kind of 'proto-professional' in cases of the treatment of a predisease. A good example is the establishment of what is called the 'Metabolic syndrome'. This syndrome was first described by Gerald Reaven from Stanford University in 1988, for the clustering of high blood pressure, high cholesterol, high insulin levels, and fat around the middle (lateral obesity). However, in the course of a decade there emerged many definitions and attacks from various stakeholders with as a final result that the food, pharmaceutical and diet industries, cardiologists, and diabetes experts all use different definitions. It is striking that the metabolic syndrome is not really associated with a patient group, probably because the syndrome includes so many different things. The drugs industry started to develop drugs for the metabolic syndrome, and has a major interest in using a vague definition: 'A society dedicated to addressing the condition has been organized, a journal has been started, and an education campaign launched. Patients are already being tested for metabolic syndrome. As the trade publication Pharmaceutical Executive stated in its January 2004 issue: "A new disease is being born" ' (Breitstein, 2004).

According to House of Commons report (HoC, 2005) on the influence of the pharmaceutical industry, it is not only this industry, but also associations of physicians and the patients themselves that all too easily embrace new diseases and their concomitant drugs. It stresses that the industry has encouraged this 'medicalisation' by acting as a 'disease monger', with the aim of categorising an increasing number of individuals as 'abnormal' and thereby requiring (drug) treatment. This process has led to an unhealthy over-reliance on, and an overuse of, medicines. It also diverts resources and priorities from more significant disease and health problems.

> What has been described as the 'medicalisation' of society – the belief that each and every problem requires medical treatment – may also be attributed in part to the activities of the pharmaceutical industry. 'While the pharmaceutical industry cannot be blamed for creating an unhealthy reliance on, and over-use of, medicines, it has certainly exacerbated it. There has been a trend towards categorising more and more individuals as 'abnormal' or in need of drug treatment.' (p. 6) 'Medicalisation could lead to unsustainable demands on the NHS, a confused vision of how good health is maintained and a failure to ensure preventative public health measures are at the forefront of health policy.' (p. 9)

The report mentions a number of disadvantages like: 'Witnesses argued that the use of disease awareness campaigns, which in the past have involved conditions including depression, anxiety and obesity, plays a major part in the 'medicalisation' of our society; in short: "where disease awareness campaigns end and disease mongering begins is a very indistinct line." ' (p. 71)

We have never been so healthy, but are told we are sick. We are all 'pre-sick' or in a constant state of 'predisease'. Fewer and fewer people are said to be healthy and well. This can be a distressing prospect for children in particular: to be constantly reminded of being in a state of predisease and in need of continuing diagnoses. Children need future prospects, in particular with respect to such very fundamental and intimate things as their bodies, which they need to be able to trust under all

circumstances. The urge to look for obese children or children vulnerable in this respect clearly has a down-side.

Moreover, the normal standards that people have for being healthy have become questionable. Normally, one is healthy when one doesn't feel anything and is not reminded of bodily restrictions. The functioning of the body contributes to a feeling of well-being if the body doesn't send messages that something is going wrong, e.g. a pain signal or a refusal to do things you normally do. However, a prediseased state has been disconnected from feelings of pain or other signals that tell you that you are ill. Now it is the test that tells who you are. In a certain sense, people will have to be re-educated on the new standards of being healthy and 'normal'.

However, these fresh standards often change, for example: the level of normal cholesterol has been reduced multiple times; for more reflection on the uncertainty of these new standards on being healthy, see below.

There are some sectors in society that profit from this drive towards prevention of all kinds of ill-health. For example, Fredric Abramson, founder and CEO of AlphaGenics (Rockville), 'sees the food industry as a natural partner in developing products that could, for example, target broad-spectrum conditions such as menopause or breast cancer.' (Amanda Archibald, June 1, 2004, Nutrasolution.com). Selling drugs for risk factors instead of diseases is very profitable for the industry. Taking into account that many of them also provide tests Roche, for example, is one of the biggest providers of tests and drugs- it means that there now is a structure for labelling healthy people as potentially unhealthy or even abnormal.

Third, there are too many genetic variations and rather vague associations between symptoms and diseases. This means that there are too many tests on the market which no one can have a clear insight into as to what they actually test (p. 76; p. 103, see Chapter 8). The HoC ends its report with the recommendation: that it is strongly advisable to do 'Research into the adverse health effects of medicalisation' (p. 121).

Lynn Payer addressed this issue in the early 1990s in her book *Disease-Mongers: How Doctors, Drug Companies, and Insurers Are Making You Feel Sick*. She wrote: 'Disease-mongering – trying to convince essentially well people that they are sick, or slightly sick people that they are very ill – is big business. . .. Disease mongering is the most insidious of the various forms that medical advertising, so-called medical education, and information and medical diagnosis can take.' Others, like Howard Wolinsky (2005), agree with this diagnosis, and indicate how much industry can profit from manufacturing prediseases. Again, this paradox requires new types of regulation (and the abolishment of the older, no longer relevant ones!).

In Chapter 13 we have discussed the prevention paradox as identified by Rose, which signifies never to concentrate on the group of high risk persons, but always on the more general types.

The *third paradox of ambiguities* covers the increasing awareness that the genomics treatment of obesity comprises not a clear cut methodological program, and that implies that promises and disappointments about presumed causal gene-diet

relations abound. Scientific findings on gene-environment interactions are inherently ambivalent: genes can express themselves in different, often contradictory ways; we have discussed this in Chapter 15. Ambiguities galore and make ethical decision-making an issue of deliberation, not of producing a final decision. Ambiguities and uncertainties as the main products of science and technology dealing with complex problems don't require definitive answers, but do require processes of interaction between scientists and stakeholders, comparing and provisionally assessing the potential knowledge, products and services. *The third paradox is: science brought in to provide certainty, produces more uncertainties.*

Finally, the *fourth paradox* concerns the regimes of data management and their unclear functions and mandates. Scientists and other professionals collect a great number of data, but don't always know what can be done with them. The head of Novartis' pharmaceutical business unit laments: 'data, data, data everywhere and not a drug.' (Pollack, 2010) The interpretation of these data is very often a puzzle, for the expert and for the non-expert but involved lay person. For this type of person it is often impossible to make sense of the information produced, because of the fact that the informational data are produced from a framework that was not designed with consumer and patient preferences and frameworks of meaning in mind. So *the fourth paradox is*: *the more information is collected, the more its meaningfulness becomes a problem.* One proviso is necessary here: not all genetic information fundamentally forms a riddle, and not all information is in-depth regarding identity and personality. Sometimes only occasionally relevant surface information is collected. However, in particular when on preventable diseases, information becomes more important and laden with additional layers of meaning. Depending on the perceived severity and preventability of the disease one will frame the information differently.

Outlook and Conclusion: Ethical Implications of the Co-evolution of Genomics, Social Order and Values

In the last chapters, considerations are given how to foster fruitful reciprocal and balanced development of genomics and of social and ethical norms, strategies and institutions ('a happy match'). The notion of deliberative learning process played in those considerations a crucial role, with its concomitant concepts of voice, exit and access that can produce a fair representation of life- and food styles in genomics innovation trajectories. Voice does not only concern deliberation on technologies but also the possibility of shaping new opinions, of looking for new vocabularies, of experimenting with norms and values, and of getting the information one views as relevant (information preferences). Access covers deliberation and experimentation: the creation of new boundaries and experiments with new arrangements of technologies and norms.

By applying these three types of rights in concrete deliberations and consultations, one can identify the opportunities for new forms of cooperation by co-managing technological alternatives and selecting ethically desirable alternatives from the possible scenarios. We conclude that living a good life in a world with

genomics products and services like high tech food and drugs, implies the deployment of procedural and substantive aspects. Both the rights of voice, access and exit and the normative values of living and cooperating together require an expanded individual consent, but not the consent of collectives. Collectives can't vote or act, only individuals can, and all trials to have collectives act, are actually disguised forms of certain dominant individuals' actions. Embedding high tech food should mean establishing connections with social interactions of peaceful and meaningful actors (Tables 16.2 and 16.3).

Table 16.2 The current script of nutrigenomics is matching with only one of society's life and food styles (values) (see also Chapter 10)

Currently: genomics	Obesity and social order	Responsibilities	Norms and values
Gene-environment; (no) cure, (no) prevention	Behaviour Environment Body	Individual responsibility	Health as dominant in life and food style

Table 16.3 The potential co-evolution of genomics, social order and norms/values, with responsibilities and fair representation as 'bridge' concepts

Genomics	Obesity and social order	Responsibilities	Norms and values
Gene-environment; (no) cure, (no) prevention	Behaviour Environment Body	Genetic responsibility; fair representation	Traditional, Egalitarian, Individualist, Eclectic life and food styles

After our exploration of the potentialities of genomics in treating obesity, we conclude that cognitive and normative 'mistakes', ambiguities and uncertainties are numerous and inevitable. Genomics as important ingredient of innovations applied to the problem of obesity wrestles with social institutions that are yet not in proportion or in balance with the social institutions it requires and with the food- and life styles that currently are dominant in society. This imbalance can be met in three ways. First, one can chose for the 'science' pole op the balance by imposing the social institutions that seem to be in line with genomics and by favouring the food- and lifestyles that frame health as the most important value in life. A second strategy can be to give in to current institutions and dominant food- and life styles and to give up current science. A third strategy can be the positive stimulation of development in science, social institutions and food- and life styles in order to create room for reciprocal positive developments and a happy match. The concept of fair representation introduced here is meant to focus on the last possibility and to stimulate and synchronize the co-evolution of science and the social and normative order.

On the basis of the current vocabularies inherent in nutrigenomics innovation trajectories towards obesity, we have formulated four paradoxes:

- *The first paradox is: individualization is also a new type of collectivization.*
- *The second paradox is: prevention leads to aggravation and medicalisation.*
- *The third paradox is: science brought in for providing certainty, produces more uncertainties.*
- *The fourth paradox is: the more data are collected, the more their meaningfulness becomes a problem.*

For individuals this implies that they will have to try and find a balance between individual and societal approaches, between cure and prevention, between certainties and uncertainties and between information and meaningful information. This also means that they will have to deal with ambiguities and (un)certainties of the utmost importance, and shift the more important from the less important ones. For researchers, this would mean that they take into account the selective value of their vocabularies and scripts and try to balance these with other vocabularies and scripts. For governments this implies that in certain areas they will have to make tough decisions, like making clear distinctions between food, medicine and a grey zone and subsequently do a lot of regulatory work for this grey zone. Moreover, consultation with the public is necessary. Also, governments should see to it that public health research and care remains the most important item in the research agenda for nutrigenomics. Finally, the public should be involved in the deliberation on upstream nutrigenomics developments, not only downstream on the services, products and biobanks. All in all, individualized nutrition needs strong governments.

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