

## Scientific Contribution

### Geneticization and bioethics: advancing debate and research

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**Abstract.** In the present paper, we focus on the role that the concept of geneticization has played in the discussion about health care, bioethics and society. The concept is discussed and examples from the evolving discourse about geneticization are critically analyzed. The relationship between geneticization, medicalization and biomedicalization is described, emphasizing how debates about the latter concepts can inspire future research on geneticization. It is shown how recurrent themes from the media coverage of genetics portray typical traits of geneticization and thus contribute to the process. We look at examples of small-scale studies from the literature where geneticization of medical practice has been demonstrated. Methodological disputes about the relevance of empirical evidence for the geneticization thesis and the normative status of the concept are discussed. We consider arguments to the effect that ideas from mainstream bioethics have facilitated geneticization by emphasizing individualistic notions of autonomy and responsibility while ignoring the role of genetics in the wider social context. It is shown how a concept like geneticization, which can be used to draw the attention of philosophers, social scientists and others to challenges that tend to be neglected by mainstream bioethics, also has the potential to move people's attention away from other pertinent issues. This may happen if researchers become preoccupied with the transformative effects of genetics, and we argue that a wider reading of geneticization should inspire critical analysis of the sociocultural preconditions under which genetics is currently evolving.

**Key words:** bioethics, geneticization, genetics, medicalization, responsibility

#### Introduction

Discussions in the field of bioethics have increasingly been dominated by issues relating to genetics and its various effects upon health care and society. These discussions have both influenced some of the traditional topics of biomedical ethics and created new ones. One way to estimate the influence of genetics on bioethical discourse is to try to discern whether there are some underlying modes of thought, types of language and cultural processes, which are characteristic of the development. It has been argued that such typical traits and processes are part of a more comprehensive trend labelled geneticization. In this paper we intend to critically analyze the concept of geneticization and how the concept has been used and debated in discourses about health care and bioethics. We also point towards issues where further research in this area could be advanced.

We will start by placing the concept in a historical context, show how it has appeared in the discussion

and estimate its relation to other similar concepts like medicalization and biomedicalization. We consider examples from prevailing discourses about the promises of genetics in the public media and in policy debates, as well as examples of how the concept of geneticization has been used in analyses of genetic research and clinical practice. The debate about the relevance of empirical evidence for the geneticization thesis and its relation to philosophical interpretation of the process is discussed. We critically evaluate arguments to the effect that mainstream bioethics has paved the way for geneticization by a narrow understanding of its role and concepts. In relation to this, we discuss the suggestion that the concept of geneticization is suited to expand the focus of bioethical efforts, and increase the sensitivity of bioethics to social issues, e.g. by complementing a rather narrow focus on autonomy and responsibility in an individualistic rendering.

Finally, we discuss the criticism which has been put forward that the concept of geneticization

tends to direct researchers' attention towards the consequences of developments in genetics and reduce their sensitivity to the preconditions under which this development takes place. It seems to us that recent discussions about medicalization and biomedicalization demonstrate an awareness of complexity, multivalency, power struggles and 'horizontal' power which can also be fruitfully applied to geneticization. Although many social scientists and philosophers seem to accept the transformative nature of the new genetics and its discontinuity with genetics in earlier times, the concept of geneticization requires that we pay close attention to the social circumstances under which genetics is evolving. A number of insightful studies combining empirical investigation, moral reasoning and philosophical interpretation have already been conducted, and contemporary debates about medicalization can provide weighty inspiration to the task of advancing bioethical efforts in the field circumscribed by geneticization.

### Geneticization

The concept of geneticization has been used by social scientists, philosophers and other scholars for almost two decades. The first occurrence of the concept is in a paper with the title "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities" by Canadian researcher Abby Lippman published in 1991. In the following years, Lippman has expanded on the same theme in many publications and lectures, namely that the recent rise of human genetics has unfortunate consequences for individual and societal perceptions of reproduction and prevention of disease, and even on the conceptualization of human agency in general. Several other authors have published research and commentaries in the same vein. Some refer explicitly to the concept of geneticization, while others employ related concepts like genetic essentialism or genetic determinism. The strongly normative critique posed by Lippman and those sharing a similar agenda has been called into question by other authors. Debate about geneticization has in part come to evolve around the empirical basis of the critique as well as methodological questions about how the validity of the geneticization critique shall be ascertained. Another strand of the debate focuses on the suggestion that the strongly normative use of the concept should be abandoned in favour of a more analytical and ethically neutral approach towards

the sociocultural phenomena that are to be illuminated with the concept of geneticization.

Different interpretations and disputes about the utility of the concept of geneticization are historically and conceptually related to the ways in which the somewhat older concept of medicalization has been used and debated. In a similar way as medicalization, the concept of geneticization was introduced in an uncompromising critique of prevailing optimism about the healthcare services and biomedical research. In both cases, the empirical basis as well as the normative focus of the critique has been called into question. As the concept of medicalization is the older of the two, and this concept has been employed in politically important debates about medicine and healthcare in recent decades, we will recall some essential points from the history of the concept of medicalization and consider the relationship between the two concepts. Before that, however, let us give a broad outline of how this concept has been used by Lippman and others who basically share her points of view.

As introduced by Lippman, geneticization is a process by which "priority is given to differences between individuals based on their DNA codes". Geneticization is cast as a highly unfortunate phenomenon, in part because, if not universally then at least in racist, sexist or otherwise segregated society, "genetic ... studies which look for differences between socially constructed groups ... cannot but reinforce stereotypes and prejudices, and even impede understanding of health differences between individuals" (Lippman, 1999). Lippman argues that genetics is "increasingly identified as *the way to reveal and explain health and disease, normality and abnormality*". Further, using prenatal diagnosis as a prime example she argues that geneticization involves directing intellectual and financial resources towards high-tech ways of resolving health problems and creating an atmosphere of reassurance and control for the privileged, at the expense of "low-technology" approaches towards societal and political determinants of health which would have greater impact for the underprivileged (Lippman, 1991).

In addition to Lippman, certain authors are frequently mentioned who have argued that fascination with genetics brings about unfortunate consequences. Actually most of these authors do not use the concept of geneticization as their analytical focus. Nevertheless, a common denominator shared by these authors seems to be a concern about undue individualization of health

with a corresponding disregard for social, environmental and political determinants of health. Furthermore, it is argued that the rise of genetics is linked to unfortunate definitions of personhood, identity, relationships, power and responsibility. We will briefly recall the main arguments of a couple of these authors only, while other authors, such as Hubbard and Wald, Van Dijck and Duster, will be left aside although their points of view are certainly not without interest. In *The book of life: a personal and ethical guide to race, normality, and the implications of the human genome project*, Barbara Katz Rothman writes about the danger that the ideology accompanying the current rise of genetic research and genetic technologies promotes racist injustice and discrimination (Rothman, 2001). Furthermore, although explicitly acknowledging the life-saving benefits many patients receive from medical genetics, Rothman argues that in other cases individualizing disease by focusing on its genetic component obscures the role of the social and political world in causing disease. In addition, Rothman fears that genetic technologies will be used in attempts to gain control over our future through manipulating human procreation in ways that intimidate individuals and weaken the socio-cultural resources needed to grapple with the challenges of human existence.

Nelkin and Lindee's study of how genes and other genetic concepts or images are used in popular culture in the USA is also among the sources frequently referred to in discussions about geneticization (Nelkin and Lindee, 1995). Nelkin and Lindee maintain that genetic essentialism, or the belief that genetic features are decisive for how and who we are, is on the increase. To substantiate this claim they state a wide range of examples from their analysis of popular culture or 'folklore' in the USA. We will return to a critique of Nelkin and Lindee below. We will now turn to the concept of medicalization, which provides a historical and political background to our subject matter.

### Medicalization

Scientific and technical progress in medicine in the post-war period resulted in an expansion of bio-medical services and high expectations that medicine would alleviate human suffering. The same progress engendered a popular and professional concern about ethical dilemmas arising from the use of medical technology and the power wielded

by the medical profession. Thus arose the modern breed of medical ethics with its new focus on patient information and autonomy. However, the 1960s also witnessed a more fundamentally critical and pessimistic response against prevailing technological optimism. In the field of medicine this response came to be identified with the so-called medicalization critique. In the uncompromising shape provided by Zola and Illich (Illich, 1995), the medicalization critique included a more or less indiscriminate rejection of the benefits of modern medicine, and claims of serious harm and abuse of power in the name of healthcare. The medical profession and its affiliates were accused of being the executive arm of oppressive state and capitalist power, transforming the citizenry into docile subjects of medical interventions, obfuscating social and political determinants of suffering, reducing people's ability for self-care, hampering humanitarian response towards the suffering of others and of other injustice.

The medicalization critique has been a subject of discussion and fierce controversy. To a certain extent, the medical profession itself has adopted the habit of critically evaluating its own science and practice. Thus, the label Evidence Based Medicine signifies a systematic endeavour within the medical profession to examine harms as well as benefits for individuals and groups of patients. Other professions are engaged in the closely related disciplines of technology assessment and health economics which seek to quantify the benefits and cost-benefit ratios of different medical practices at a societal level.

However, the accusations of oppression, de-politicization of injustice and neutralization of people's inherent capacity for self-care, which are the most controversial parts of the medicalization critique, have mainly been the turf of philosophers, social scientists, and even activists, although medical writers have attended to these topics from time to time. One strand of the debate concerns the evidence for the alleged cultural and social harm caused by medicine. The sweeping generalizations of Illich and Zola have been rejected by most researchers, but it remains a challenging task to investigate whether and to what extent the expansion of medical institutions and medical ways of thinking may sometimes be associated with unfortunate outcomes on the sociocultural arena. The moral status of medicalization is another topic of debate. Instead of signifying the inherently condemnable harm caused by the medical establishment, some scholars argue that the concept of

medicalization should direct analyses towards cultural and social correlates of biomedicine without concluding *a priori* about the moral status of the phenomena that can be illuminated with this concept: Surely, medicine is expanding and medical thinking invades new areas, but it is open to empirical investigation and normative analysis to judge whether this is for the better or for the worse. Similarly, it should not be taken for granted that medicalization is a continuous process of increasing medical control or expanding use of medical models of interpreting reality. Thus, the development of psychiatry and mental health services is cited as an example of desirable medicalization, with medicine making progress and providing relief in an area characterized by stigma, prejudice and suffering (Conrad and Schneider, 1992). Conversely, the medicalization of homosexuality has in essence been reversed by an active process of demedicalization brought about by groups of people who did not find protection against stigma under the power of medicine. Similar examples are also cited to refute the view that the public is docile and easily manipulated in the name of medicine as implied in extreme forms of the medicalization critique (Williams and Calnan, 1996): People today are not passive subjects accepting scientific or state control without second thoughts. In 'late' or 'reflexive' modernity the citizens are increasingly able to reflect upon and make their own judgments about how to make use of scientific knowledge and expert services, including those offered by the medical profession.

Two final topics in the medicalization debate are highly relevant for a politically and historically rich understanding of the concept of geneticization. The first is the suggestion that in recent years the organization and practices of medicine have been subject to "technoscientific" transformations that justify the introduction of the concept of biomedicalization (Clarke et al., 2003). In this view, the incorporation of technology and technical procedures into medical practice goes hand in hand with conceptual and cultural emphasis on the transformation of the biological constitution of individuals and populations. Diseases are no longer primarily defined or conceptualized at the level of organs or physiological functioning, but at a subcellular, molecular level, as well as at a presymptomatic, statistical level of risk. The technoscientific transformation of medicine and the accompanying cultural processes are driven primarily by technological development and corporate interests rather than by the medical profession. Furthermore,

individuals integrate the demand for continuous surveillance and management of their health into their very identity. The latter phenomenon is also crucial in the school of thought evolving from the late theories of Foucault. As distinguished from state and professionally driven 'vertical' medicalization as described by Illich and Zola, the ideal of cultivating the healthy body is now being implemented through "the individual internalization of a totally medicalized view of life" (Nye, 2003). Some authors see this mainly as a liberating form of self-governance, as new spaces are opened up for individuals empowering them within a new "biosociality" (Rabinow and Rose, 2006). On a more critical view, 'horizontal' medicalization casts modern citizens into a specific mould, disciplining rather than empowering them, making self-management of health the second nature of every responsible person.

As we now turn back to geneticization, this concept has been criticised in much the same way as has the concept of medicalization in its original and uncompromising form. This relationship is made explicit by Adam Hedgecoe in an article published in 1998, with the claim that "the current state of the debate surrounding geneticization is open to many of the same criticisms that were levelled against those promoting the medicalization thesis 20 years ago" (Hedgecoe, 1998). The core of his argument is that while the claims of the proponents of geneticization may seem "attractive and intuitively correct ... they lack adequate grounding in reality". Geneticization is misused, much like its precursor medicalization was by Illich, and is to be regarded as a polemical device rather than a scientific construct. The case is consistently overstated and is not substantiated by empirical evidence which shows, for example, that genetic discourse has become less deterministic than it was. Concerning the latter, Hedgecoe relies mainly on different studies by Celeste Condit, which cast doubt on geneticization and genetic essentialism.

Thus, according to Hedgecoe (2001), "the geneticization thesis is flawed due to its 'moral circularity'", i.e. those concerned about genetic determinism and reductionism are *a priori* convinced that genetics is harmful, and inevitably interpret all signs of cultural influence from genetics as proof of this harm. Nevertheless, Hedgecoe does not reject the usefulness of the concept of geneticization altogether, concluding that the "solution lies perhaps in small scale studies, which focus on individual elements of geneticization, such

as its role in a single disorder, or the introduction of a specific item of genetic technology". In that way, presumably, analysts could avoid sweeping statements about cultural reality and give their results a shape which could be empirically verified.

### Examples from prevailing discourse

Questions about the relationship between philosophical ideas and concepts on the one hand and empirical facts on the other hand are at the heart of many fruitful disputes in bioethics. Below, we shall return to some of the epistemological and methodological arguments which have been raised in response to Hedgcoes's claims about the lack of empirical evidence of geneticization. However, a number of studies have traced how the diagnosis and conceptual understanding of specific diseases has changed as a result of advances in genetics. Such studies, which correspond more or less to the suggestion made by Hedgcoes, address the geneticization of diabetes, heart disease, schizophrenia, cystic fibrosis and  $\beta$ -thalassemia to name a few diseases. In some studies the focus is mainly on how the medical epistemology of the disease in question is affected by advances in genetic research (Hall, 2005; Hedgcoes, 2004; Kerr, 2005). Thus, one study documents that when molecular genetics enters into a multifaceted debate among researchers investigating the causes of hypertension, claims about heart disease being genetically caused are contested by different researchers (Hall, 2005). The professional understanding of cystic fibrosis on the other hand has undergone more of a one-way development from a collection of symptoms and gross features, through a technoscientific transformation into a collection of molecular and genetic pathologies (Kerr, 2005). Nevertheless, this development has also occurred in a piecemeal fashion, with researchers, patient groups and clinical doctors playing diverse roles. And the geneticization of cystic fibrosis has not led to a 'simple' genetic definition of the disease being used uniformly throughout clinical medicine and prenatal diagnosis. Although proposals have often been made that cystic fibrosis is a one-gene disease inherited in a Mendelian fashion, its clinical manifestations show great variability, and the genetic and molecular mechanisms underlying this disease are now thought to be complex and heterogeneous, even to the point that "genetics does not simply clarify or confound the nature of the disease. Indeed, the very notion of CF as a genetic disease is open to

multiple interpretations, now as in the past" (Kerr, 2005).

Another main focus of small scale studies is the change in self-perception brought about for patients and individuals-at-risk through genetic research (see Kerr, 2004 for an overview; e.g. Meiser et al., 2005) or even more encompassing societal changes when preventive genetic counselling and other social interventions are introduced (Hoedemaekers and ten Have, 1998b). In the latter study it is argued that a "concerted action of public health authorities, medical professionals and parental associations to promote carrier screening and (later) prenatal diagnosis" led to an efficient reduction of new  $\beta$ -thalassemic patients in Cyprus. While individuals make the final decisions, this concerted action created a web of social control in the management of the disease which had a major effect on the parental decisions. This makes it difficult to determine the locus of responsibility for decisions to terminate pregnancy in the wake of genetic screening. It is in the hands of health care professionals to design the tests and present the options to couples, and they tend to emphasize the burdens, costs and limitations at the exclusion of other factors. The authors conclude, therefore, that medical professionals are largely responsible for creating "a directive decisional framework" for the prospective parents.

To summarize, some of the available small scale studies of geneticization have shown that the introduction of genetics into the epistemology of different diseases does not always lead to the full abandonment of older and more complex conceptions of the diseases in favour of a more simple and reductionistic genetic definition. On the other hand, the study of  $\beta$ -thalassemia shows that simple genetic definitions can in some cases gain hegemony, and in such cases, the consequences of geneticization for the populations involved are formidable. This again raises the issue of the broader cultural aspects of geneticization, such as those pertaining to alleged injustice, stigmatization and disregard for the social determinants of health and disease. Obviously, insofar as small-scale studies focus exclusively on geneticization as a feature of medical epistemology, they will not resolve these broader concerns.

### Representations of genetics

We now turn to the way in which genetics is portrayed and debated in the public arena. This

topic has been extensively studied by social scientists and other researchers in many countries in recent years, and such studies form a crucial part of the broader evidence to be considered in order to gauge the extent to which geneticization is currently taking place. The most extensively studied field is probably the print news media portrayal of genetics, but other news media and different outlets of popular culture have also been investigated. Furthermore, to some extent research has focused on the way geneticists and other professionals describe and debate their own activities, for example in science editorials and in policy documents. Due to space limitations we will only touch on a few aspects of the way genetics is portrayed and debated in the public sphere. It should be emphasized that the studies and their results in this field are quite diverse, and the picture to be gathered from a thorough acquaintance with this kind of research displays complexity and nuances which we cannot adequately report here.

As the Human Genome Project gained momentum in the 1990s, genetic research frequently reached the headlines of the popular news media in many countries. Sensationalist portrayals of the benefits of genetics were common and progress was framed as inevitable. Concerns often evolved around the “race” between the public and the commercial strands of the Human Genome Project, or around ‘downstream’ ethical challenges related to the use of genetic technologies-to-come. Prominent authorities usually gave their unconditional support to genetic research, as on the strongly publicized event of the draft completion of the Human Genome Project in 2000 when president Clinton and prime minister Blair both displayed great enthusiasm for the potential of genetics to revolutionize healthcare and asserted that genetic research was essential for the leading role their countries play in the field of science and medicine (Nerlich et al., 2002). Similarly, in policy debates healthcare officials and political authorities have often sought to assure that healthcare will continue to improve through advances in genetics. Thus a white paper by the British government states that “genetics offers enormous potential to improve our health and healthcare – more personalized prediction of risk, more precise diagnosis, more targeted and effective use of existing drugs, new gene-based drugs and therapies, and prevention and treatment regimes tailored according to a person’s individual genetic profile” (Department of Health, 2003). Similar arguments have been strongly promoted by scientists such as Francis

Collins, leader of the public arm of the Human Genome Project in the USA. One of Collins’ agendas in different articles in leading professional journals has been to prophesy that genetics is about to enter “the medical mainstream” (Collins and Guttmacher, 2001) and to mobilize support for a comprehensive curriculum in genetics for all healthcare professionals. Editorials in high impact medical journals have also been shown to share the view that the progress of genetics is inexorable and that the benefits for healthcare will be great (Miller et al., 2006). Conflicting points of view have been promoted in a smaller number of opinion pieces in medical journals (e.g. Holtzman and Marteau, 2000), but have hardly been noticeable in editorials of the medical professional press.

A number of studies have investigated whether the popular news media or other arenas of popular culture and public debate increasingly portray human fate as being controlled by genes, and whether genetics is increasingly framed as the provider of solutions to human suffering. Among these, a broad study by Nelkin and Lindee of popular culture in the US is frequently cited. In a book called *The DNA Mystique: The Gene as a Cultural Icon*, Nelkin and Lindee maintain that in popular culture the gene has become “a way to explore fundamental questions about human life, to define the essence of human existence” (Nelkin and Lindee, 1995). Although Nelkin and Lindee base their claims on an analysis of large amounts of sources including broadcast media talkshows, comic books and science fiction, their conclusions have been criticized on methodological grounds (Hedgecoe, 1998). Their study includes no quantitative analysis of the frequency with which expressions of genetic essentialism occur in popular culture over time. Similarly, their study leaves out the occurrence of expressions going against genetic essentialism. Thus, whereas Nelkin and Lindee’s study documents that simplistic expressions about the absolute power of genes do occur in the public domain, no conclusions can be drawn as to whether such expressions have become more frequent in recent years or even whether they are a dominant theme in popular culture. Other scholars have actually performed such longitudinal studies seeking to analyze how the balance between ‘essentialist’ or ‘determinist’ portrayals of genetics on the one hand and more multivalent or complex portrayals on the other has changed over time. Among these, a longitudinal study by Celeste Condit and co-authors (Condit et al., 1997) which indicates that geneticization or statements of

genetic determinism have not become more prominent in the popular media in the US from 1919 to 1995 has frequently been cited.

Another category of media studies relevant to the discussion of geneticization are those focusing on the portrayal of human genetics in the news media in the years leading up to and following the Human Genome Project. Most of these studies do not have a longitudinal focus, but rather seek to identify common themes and ways of portraying human genetics, linking them to positive or negative values, enlisting enthusiasm or raising concerns (among others Bubela and Caulfield, 2004; Conrad, 1999, 2001; Kitzinger et al., 2002; Petersen, 2001; Racine et al., 2006; Tammpuu, 2004; Väliverronen, 2006). According to these studies, the pursuit of human genetic technologies is usually portrayed as being desirable – the technologies hold great potential for alleviating and preventing suffering and are likely to yield financial benefits. Genetic technologies are expected to result in improved medical services and individual control over health. The role of broader environmental and social factors in disease is usually not discussed alongside the genetic aspects. A range of concerns is nevertheless included, mainly regarding tampering with nature, discrimination of individuals, and revoking eugenic atrocities of the past. Coverage of genetics is typically of an either-or nature, and attempts to balance the potential benefits and dangers are rare. The framing of technology's ethical and social implications is dominated by scientific and political experts, and scientific disagreement about research findings or the principles on which research is conducted is seldom reported. Journalists infrequently question research findings or predictions about benefits. The regular occurrence of dystopian themes allows scientists to assure that their own research is of the right kind and is subject to appropriate regulation, and thus serves to highlight the ethical standards and the beneficial implications of human genetics.

### Evidence and interpretation

We previously cited a claim made by Hedgecoe (1998) that the geneticization thesis is a polemical device without adequate grounding in reality. According to Henk ten Have (2001), this claim “is a symptom of the same phenomenon identified and criticized in the geneticization thesis, *viz.* the uncritical predominance of mechanistic and reductionistic images”. The reason is, ten Have argues, that

Hedgecoe takes the explanatory model of the empirical sciences as the only acceptable theoretical framework. As a consequence, important and even pervasive cultural phenomena will inevitably escape his sociological analysis. Henk ten Have defends the thesis that geneticization is “a philosophical interpretation of the self-understanding of today's human life and culture” and not “a sociological explanation of the facts of scientific and everyday-life reality”. Although we agree with this criticism of Hedgecoe's narrow understanding of geneticization, it implies a strong bifurcation of sociological explanation on the one hand and philosophical interpretation of human self-understanding on the other hand. Henk ten Have writes that “the old dichotomy between ‘Erklären’ and ‘Verstehen’ is relevant” in this context. But as Max Weber showed convincingly, a successful analysis of cultural phenomena requires both interpretive understanding and empirical substantiation (Weber, 1949).

Much like ten Have, Hoedemaekers maintains that the geneticization thesis “is not a sociological explanation of new phenomena” (Hoedemaekers, 2001). He regards it as “a more philosophical”, “explanatory concept” which enables us to change our perspective and see issues that tend to escape our attention in the moral debate about genetics. However, Hoedemaekers also points out that geneticization is “a process of social change found at different levels” and that “research into this process has hardly begun”. We agree with his observation that such research “will probably benefit from insights in more general processes describing the interactions of science and society”. But this shows in effect that a sharp distinction between the role of philosophical analysis and sociological explanation in the task of trying to understand the cultural processes of geneticization is not helpful. In fact, both ten Have and Hoedemaekers have made significant contributions not only to the interpretation of geneticization but also to empirical substantiation of the process. Other work of these authors (Hoedemaekers and ten Have 1998b), demonstrates that interpretation and explanation need to complement each other in a successful analysis of geneticization.

The interesting hermeneutical problem raised by these writers concerns the complicated relationship between “empirical reality” and comprehensive theoretical or interpretive ideas like geneticization. It is implied in their arguments that geneticization cannot simply be ‘found’ in empirical reality or ‘read off’ cultural processes regardless of the conceptual framework that guides our understanding

of these phenomena. As mentioned above, Hedgecoe, on the other hand, warns against the tendency to ‘read into’ empirical reality features that reflect ideological bias and polemical intentions rather than actual processes (Hedgecoe, 1998). These are important warnings against two extremes, but the proponents of each tend to go quite far in the other direction. While Hedgecoe requires empirical proof, ten Have states that there “is a mistake in requiring empirical proof”. He takes as examples of such mistakes when the studies of medicine by Foucault and Illich are rejected for lack of empirical evidence. Surely, such studies of the comprehensive processes of medicalization and geneticization cannot be proven or refuted in the strict sense. But while acknowledging the limits of empirical inquiry it also is important to confront and support such interpretive ideas with empirical evidence and relevant data insofar as it is possible.

It is essential to recognize, however, that the data will inevitably be ‘theory laden’ and probably would not be ‘found’ without the relevant preconceptions. One is reminded of Novalis’ words: “Theories are nets: only he who casts will catch” (Popper, 1968). This important hermeneutical reminder implies not only that we will find no traits of geneticization in reality unless we have an idea about what we are looking for, but also that we will cast our theoretical nets in vain if there is nothing in reality to catch. Moreover, geneticization seems to be a clear example of a process which is affecting both our mode of thinking and self-understanding as well as the reality which we are trying to understand. It has, in other words, already shaped the net and coloured the catch. And now we have to be careful not to get entangled in the metaphor net which implies a rather sharp distinction between thought and reality, even though it is attentive to their interrelations. The empirical reality which we are trying to understand in this context is more than anything else a reality of concepts and ideas, arguments and explanations, imagery and attitudes. This is the cultural reality which shapes our self-understanding and hence gives direction to our actions. In the next section we will look at one manifestation of this in the field of bioethics.

### Geneticization and bioethics

Rogeer Hoedemaekers (2001) sees the main role of geneticization as a philosophical concept to enable us to “change our perspective in moral debate”. Its

fruitfulness in this regard is that it “draws our attention away from individually oriented moral issues to larger socioethical issues”. Hoedemaekers fleshes out this point by showing how the practice of technology assessment could include “broader societal effects” in addition to evaluating more particular aspects like “effectiveness, safety, costs and potential harm”. In a similar vein, Henk ten Have (2001) argues that geneticization can be regarded “as a heuristic tool in the moral debate” and that it requires that we seriously reconsider “the dominant bioethical discourse with its emphasis on individual freedom to choose”. In order to illustrate his point, ten Have focuses on two examples: The demand for non-directiveness in genetic counselling and how the ideal of individual responsibility for personal health has been perpetuated by the increased availability of genetic information.

This is an interesting and important argument because it is intended to show how prevailing attitudes in bioethical discourse pave the way “towards a geneticized future”. The dominating theoretical approach in bioethics is said to be characterized by a consensus concerning ideas which are prerequisite for norms and attitudes which will increasingly characterize human behaviour and interaction. The reasons for this, it is claimed, are mainly that mainstream bioethics discourse is too individualistic and that its analytical tools are too narrow to capture the encompassing societal processes of geneticization. In this way, bioethics is imputed with both an ideological and legitimating role in the cultural process of geneticization. It is ideological in the sense that it implicitly covers up important moral aspects of the effects of biotechnology while claiming to analyze its main ethical implications. It has a legitimating role in the process because technical innovations are only implemented if they withstand the scrutiny of ethical review and assessment which are impregnated with the dominating ideas of mainstream bioethical discourse.

Together, these functions of bioethics contribute to construing people “as autonomous individuals rather than as citizens as part of a collective, which limits ‘the spaces of action’ open to them” (Hoeyer and Tutton, 2005). Hoeyer and Tutton argue that this criticism refers primarily to a particular type of “language game” that has evolved within regulation of biotechnology and genetic research. At its worst, ethics is reduced to a mere “checklist approach” (Árnason, 2005) which has nothing to do with philosophical bioethics. We



agree with the criticism, that certain approaches in philosophical bioethics can inadvertently also play a legitimating role in the geneticization process, e.g. by narrowly focusing on employment of concepts and arguments within the prevailing discourse while neglecting the broader social context. Such ethical approaches can surely be critical in their own way although their critical analyses are relatively limited seen from the larger perspective of geneticization. On the other hand, it can be misleading to generalize about the relationship between geneticization and 'mainstream bioethics' because it is not clear what the latter term implies. There are various perspectives and controversies within bioethics which cannot be easily placed under one hat.

It would take a major study, therefore, to try to assess whether and to what extent this interesting critique is a valid observation of the dominating ideas of bioethical discourse and its effects on the socio-cultural processes of geneticization. Here we will only look at a few examples, which indicate the complexity of the relationship between bioethics and geneticization. In a joint paper, Hoedemaekers and ten Have (Hoedemaekers and ten Have, 1998a), discuss the commercialization of genetic services and describe the negative aspects of this process in terms of inadequate information. One of their conclusions is that "the interests of the patient are best served if all known uncertainties, risks and dangers are disclosed". Insofar as this argument can be translated into the geneticization issue, it indicates that the major force behind the process is commercialization and that the role of bioethics is to criticize the evolving practices when they "threaten important individual values, notably free choice and privacy". In this context, the heuristic role of geneticization in the moral debate could be to place these individual values in a larger social context. It is an open question, however, whether such contextualization "poses a challenge to the dominant practical bioethics" (Hoedemaekers, 2001), or whether the broader societal approach would be complementary to the emphasis on individual values. If these values are themselves among the key elements which facilitate geneticization it is hard to see how the two approaches could complement each other. And then one must ask what becomes of the individual values such as autonomy, consent and privacy in this context. Are they obsolete or misleading as such or only in a certain individualistic form which disregards other aspects?

Judging from the examples intended to portray the limits of bioethical discourse – technology assessment, non-directiveness, individual responsibility for health – it becomes clear that it is not the basic bioethical values themselves but primarily a narrow understanding and employment of these notions which are being criticized in the discussion of geneticization. As for technology assessment, the point is mainly that the focus is too much on individual issues while "broader societal effects tend to be neglected" such as how "the domain of science and technology influences and even transforms important moral and cultural values" (Hoedemaekers, 2001). As demonstrated above in the Cyprus example, this cultural transformation, in turn, frames as well as counteracts the alleged voluntary decision making process.

In light of this, the demand for professional non-directiveness in order to respect individual autonomy is quite limited and provides, for example, "a weak counterbalance to tendencies to make genetic tests more generally accessible" (Ten Have, 2001). This does not mean, however, that the bioethical notions of non-directiveness and autonomy are of no use in this context. As has been pointed out (Oduncu, 2002), there may be a general consensus about providing non-directive counselling. But "there is no accepted common definition of what non-directiveness really is or ought to be". It has also been argued (Rentmeester, 2001) that individual self-determination can be better served by avoiding value neutrality in genetic counselling than by the practice of non-directiveness. Furthermore, while individual choice and personal autonomy have played an important role in the legitimacy of prenatal diagnosis, this practice has "implications that may negatively influence the freedom of the persons involved" (Hildt, 2002). Clearly, there can be an important distinction between counselling in relation to prenatal genetic diagnosis and clinical genetic counselling, especially in cases where the latter concerns options of treatment which is rarely the case in prenatal diagnosis. In those cases, it can be argued that the norm of non-directiveness is "inadequate from a medical point of view" because they are "aimed at promoting health and ameliorating disease" (Ten Have, 2001). This is much more debatable and complex in genetic counselling in the wake of prenatal diagnosis where people need to decide whether to continue or to terminate a pregnancy. In such cases, other more important features of geneticization come to the fore.

In light of this discussion, it seems to us that the relationship between geneticization and the prevailing trend in mainstream bioethics which is usually referred to as ‘ethics of principles’ is far from obvious. It partly depends on how the principles are understood and how they are used in bioethical discussion (Häyry, 2003). The issue of autonomy, for example, is a complex philosophical matter and its identification with individual choice based on informed deliberation is only one expression of it which should not be taken as a universal model, even though it has been prominent in mainstream biomedical discussion. It could even be argued that this particular mode of respecting autonomy can in some cases undermine agency which is the underlying interest of the principle. The ‘problem’ with the four Georgetown principles, for example, is not which principles are put forth but rather that they are often simplistically applied and identified with a certain individualistic interpretation of the underlying values.

We see no inherent tension between emphasizing the value of autonomy or other dominating ideas of ‘mainstream bioethical discourse’ and the heuristic reminder of geneticization to pay attention to larger socioethical issues. The contrary, it is one of the preconditions of a rich notion of autonomy not to reduce it to choices which are abstracted from the sociocultural context framing these choices. It is only when autonomy is interpreted in an atomistic way that the geneticization thesis is in conflict with the application of bioethical principles. Unfortunately, the individualistic interpretation of principles has become commonplace at the neglect of wider biopolitical and cultural issues.

The relationship between geneticization and the so-called “integrated empirical bioethics” (Molewijk et al., 2004) is also ambiguous. Empirical bioethics is largely motivated by the criticism of the application of abstract principles which tends to be inattentive to the actual practices of medicine and genetic research. The empirical turn in bioethics is, therefore, an important corrective to abstract principlism. However, some formulations of the integration of empirical work and ethical reflection have emphasized the primacy of accepted norms over reasoned principles (Scheer and Widdershoven, 2004). This leads to the search for moral guidelines in established scientific practice and in ordinary moral consciousness. The shortcomings of this approach become particularly evident when it is seen in the light of the geneticization thesis which requires that we delve ‘beneath’ accepted rules and

practices and critically evaluate them in the context of wider cultural processes. Put in the language of hermeneutics, the task is not only to understand participants’ own normative understanding and actual policies – the so-called hermeneutics of faith – but also to examine how they are formed by power and special interests – sometimes referred to as hermeneutics of suspicion (Ricoeur, 1970).

Moreover, some empirical evidence is particularly problematic from this perspective because the views people express are often largely influenced by ‘genetic ideology’, which requires careful scrutiny. Analysis of mundane moral reasoning and ordinary moral consciousness will never reach the depth necessary for unveiling the powers at work in this context (Árnason, 2005; Ashcroft, 2003). Empirical bioethics is not necessarily dependent, however, on the neo-aristotelian normative ideology of integration. Cultural processes have been analyzed in case studies which substantiate the geneticization thesis. The Cyprus study (Hoedemaekers and ten Have, 1998b) is a good example in point where actual practices are critically analyzed, partly in light of the principle of free choice without reducing it to an individualistic reading. To the contrary, the example demonstrates well the limits of placing the locus of responsibility for selective abortion on the individual decision makers. This analysis exemplifies a fruitful vision of bioethics where empirical research, moral reasoning and philosophical interpretation complement each other (Chadwick and Levitt, 1997; Levitt, 2004). The suspicious analytical tool of geneticization requires multifaceted research which avoids both normative and empirical reductionism.

### **Responsibility and normalization**

The example of individual responsibility for health mentioned above is also intended to show how individualistic bioethics has paved the way for geneticization. It is highly relevant to consider how developments in genetics have led to a shift in understanding of responsibility in this context. When the domain of choice is expanding with increasing availability of genetic information, “new areas of responsibility emerge” (Hildt, 2002). This process has also been referred to as a transfer “from chance to choice” (Buchanan et al., 2000) since what was traditionally regarded as misfortune is now within our control. But it does not follow that the choices placed in the hands of individuals in this area are as free as they are often

depicted. Paradoxically, people are increasingly confronted with choices and options while they are simultaneously subjected to cultural constraints as well as to conditions that can be both intellectually and emotionally overwhelming. As Hildt illustrates, this is particularly characteristic of developments in relation to prenatal genetic diagnosis. In this area, people are expected to make “responsible” choices which need to be justified both at the individual and social level: “it is implicitly assumed that responsible action consists in adequate avoidance of unnecessary private and social risks and burdens” (Hildt, 2002). This appeal to personal responsibility also augments the pressure on increasing the availability of genetic testing and we have a perfect example of geneticization.

The example of prenatal genetic diagnosis is instructive for many reasons. For one thing, it aims at detecting genetic abnormalities and leads in many cases to termination of pregnancy. In this way, disability due to genetic causes can be avoided and this is given legitimacy by being responsibly chosen by the individuals concerned. It thus exemplifies well one of the main features of the new genetics to do much of its work through individual decisions instead of being enforced by the authority of the state as was characteristic of the old genetics (Buchanan et al., 2000). This invites the argument that rather than employing the vertical and repressive power of the state, it is now “employed and exercised through a net-like organization” (Foucault, 1980). As Foucault argues, in these processes of normalization, individuals are not simply subjected to external authority; “they are always in the position of simultaneously undergoing and exercising this power”. From this perspective, the individuals who are the ‘vehicles’ of this comprehensive biopower are in a sense willingly carrying forth the very “mechanisms of domination”. The popular appeal to individuals to make responsible decisions fuels this process and contributes to a culture of blame when individuals fail to meet these demands.

This places many people, and perhaps pregnant women in particular, in an ambivalent position. On the one hand they are appealed to as autonomous decision makers who are to make responsible choices, while on the other hand they are subjects of a culture imbued with subtle disciplinary mechanisms. Moreover, their decision-making capacity is often undermined in these situations, both by the complexity and uncertainty of the information and by the concomitant psychological distress. “Medical information about the unborn child,

considered as value neutral within the biomedical paradigm, is thus transformed into a profound and private moral dilemma” (Getz and Kirkengen, 2003). This creates a tension which can perhaps often best be relieved by adopting the attitude that this is not really a personal choice but rather a normal process which ‘one’ undergoes, the way things are done in prenatal care. Thus subjectively personal choice can be avoided even though objectively it is used to legitimize the entire process. This aspect of geneticization by appealing to individual responsibility has been instructively fleshed out in the aforementioned Cyprus case and in several other studies (for an overview see Kerr, 2004).

Another and quite different example of a process of geneticization involving the intricate transfer of responsibility to the individual can be discerned in the discourse about the benefits that can be reaped from predictive genetic testing. Such tests are to be used to assess the individual’s susceptibility for disease in order to initiate preventive pharmaceutical and lifestyle measures for those individuals who are found to be at increased risk. Although this may in many cases be of benefit to individuals, the social advantages of such interventions would be increased if they were combined with action taken against the organizational and environmental risk factors in the formation and penetration of disease (Halliday et al., 2004). If the focus is limited to the genetic risk of individuals, the emphasis is on individual responsibility rather than for example on improving people’s working conditions or organizing transportation in ways which promote physical activity and reduce disease-generating pollution. The geneticization of preventive medicine could therefore lead to a shift of emphasis from social determinants of health – for which we are jointly responsible, to individual control over risk of getting disease (Holtz et al., 2006).

### **Consequences versus preconditions**

A concept like geneticization which can be used to draw the attention of philosophers, social scientists and others to challenges supposedly beyond the focus of mainstream bioethics, also has the potential to move people’s attention away from other pertinent issues. Sociologist Anne Kerr who is wary of the concept of geneticization argues thus: “Foregrounding the transformative effects of technologies takes attention away from the social

circumstances in which they are developed, and the extent to which they reinforce old cultural values and social arrangements, rather than introduce new ones” (Kerr, 2004). Among other things this argument questions the notion of the patient or the public as being passive subjects to geneticization. Another author critically discussing the concept of geneticization identifies an ‘impact’ model in much of the relevant research, i.e. a focus on “the social consequences of recent rapid developments in genetics and their translation into wider arenas, such as health care” (Gibbon, 2002). This potentially leaves little room for analysis of the political and social processes that lie behind the current rise of genetics as a science and an object of public consciousness, i.e. the very processes that might be the determinants of geneticization. In this view, bioethical debate often takes for granted or positively asserts the special features of genetic research, the ensuing technologies and the transformative effects of genetics. The geneticization perspective emphasizes discontinuity and states that the rise of genetics has novel consequences that are in need of management, as opposed to focusing on the continuity between genetics and our current cultural aspirations and asking whether any of the preconditions on which the rise of genetics is based are problematical.

We agree that attending to the socio-cultural context in which the current rise of genetics is taking place, bioethical efforts should not be directed towards implications of research and technology development only. In the spirit of the hermeneutics of suspicion, it must also question ‘upstream’ issues such as the ideological presuppositions on which genetic approaches are based, and the power relationships and potentially vested interests of the agents involved. On the other hand, the concept of geneticization is not necessarily synonymous with focusing exclusively on ‘downstream’ issues. As is evident in contemporary debate about medicalization (Nye, 2003) and biomedicalization (Clarke et al., 2003), we believe that all these concepts can increase researchers’ sensitivity towards a complex interplay between technology development and various socio-cultural factors, involving commercial, governmental and professional interests. It thus seems to us that scholarly debate about medicalization has moved so far since its origins with Illich and Zola that it now comprises a range of conceptual and analytical tools which can be fruitfully applied also in the case of geneticization in ways which avoid taking the transformative effects of genetics for

granted, and allow questioning of ‘upstream’ issues as well.

One unfortunate manifestation of an one-sidedly ‘downstream’ or ‘impact’ understanding of geneticization is the inclination to underestimate the extent to which predictive genetic technologies share epistemological features and practical problems with previous non-genetic approaches in preventive healthcare. For example, the success of current individually oriented preventive interventions against osteoporosis, cardiovascular disease, obesity and diabetes is far from perfect, and inevitably carries a high prize of treating and instilling concern in people who would not have fallen ill in any case. Informing people about their risk for a large number of different diseases, which they may or may not develop in the future will clearly not always be beneficial. For one thing, interpreting such information may be difficult, as in the case of understanding how little a particular genetic risk factor actually may contribute in the case of the common, complex diseases (Holtzman and Marteau, 2000) such as most types of cancer, cardiovascular disease and diabetes. Moreover, information about risk can cause distress and experienced sickness as has been discussed in the literature about medicalization. Different authors have argued that the rise of risk medicine carries a high prize, as defining subjectively healthy people as being at-risk may reduce their quality of life, and in the long run increased awareness of risk may even indirectly cause people’s health to deteriorate (e.g. Skrabanek, 1994). From a philosophical perspective, depriving the majority of people of experiencing a sense of good health, and defining them as needing professional healthcare seems to be a rather unusual way of distributing populations between normality and pathology. Moreover, as there is substantial evidence that people’s self-perceived health is a strong predictor of how their health will develop by objective standards, overwhelming information about risk may impact people’s health negatively insofar as such information causes their sense of disease susceptibility to increase.

Thus the rhetoric of discontinuity, emphasizing the advantages of genetic technologies and the astonishing impact of genetics in healthcare and at the societal level, can serve to nourish the expectation that genetic technologies aimed at the prevention of diseases such as those discussed above will not share basic epistemological features with previous medical technologies and provide flawless solution to health problems. This may

obscure the continuity of ethical and practical challenges of individualized preventive approaches, be they genetically based or not, and weaken researchers' and others' awareness that such challenges may be arising with renewed urgency as predictive and preventive genetic technologies become available.

### Concluding summary

In this paper, we have focused on the role that the concept of geneticization has played in the discussion about health care and bioethics. We have considered various aspects of the geneticization process and can summarize our main conclusions in the following points. (1) The relationship between geneticization and medicalization lie mainly in their common critique of the prevailing optimism about health care services and biomedical research by showing how they go hand in hand with unintended cultural transformations. These cultural changes affect human self-understanding and frame individual actions and decisions. Future research on geneticization should be informed by recent debates about medicalization which acknowledge the multiple interests and effects of different actors, including 'horizontal' power and other subtle influences on developments in medicine and health care. (2) The coverage of genetics in the news media or other arenas of public debate contributes to this transformation when overemphasizing the benefits that will be reaped from genetic research or portraying certain type of dangers to individuals and the human species without discussing the broader cultural or social factors. (3) The prevailing view is that genetic technologies are expected to provide personalized medical services and individual control over health. The role of broader environmental and social factors in disease is usually not discussed alongside the genetic aspects. (4) The methodological controversy about whether the geneticization thesis needs to be empirically proven tends to exaggerate the distinction between explanation and interpretation which must complement each other in the effort to understand instances of geneticization. (5) The argument that mainstream bioethics facilitates geneticization by employing notions which can neither comprehend the wider societal effects of genetics nor withstand their pressure is partly correct and partly misleading. While uncritical and individualistic bioethics can play a role in legitimating geneticization, some of the concepts of

mainstream bioethics are of major importance both in the analysis of geneticization and in protecting human interests. (6) The geneticization processes are largely channelled through changes in the understanding of responsibility for health, where individuals become vehicles of social transformation which frames their decisions while undermining human agency. The geneticization of preventive medicine may lead to a shift of emphasis from social determinants of health, for which we are jointly responsible, to individual control over risk of getting disease. (7) Although geneticization can be used to draw the attention of philosophers, social scientists and others to challenges that are beyond the current scope of mainstream bioethics, care should be taken to avoid one-sided focus on 'downstream' challenges as this may contribute to cementing cultural values and social arrangements, i.e. 'upstream' preconditions of genetics which are also in need of scrutiny. Among the 'upstream' issues relevant for the ethical assessment of genetics, as well as for the 'styles of thought' that frequently are taken for granted in the bioethics literature, are presuppositions about the primacy of individual agency and decision making in the area of health care. It seems to us that the concept of geneticization can serve an important purpose in drawing attention to these individualistic presuppositions and critically evaluating them without giving up the key notions of bioethics.

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