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Abstract

Background
Genomics provides information on genetic susceptibility to disease and possibilities for interventions which can fundamentally alter the design of fair health policies. The aim of this paper is to explore these implications of genomics from the perspective of equal opportunity ethics. Equal opportunity ethics requires that all inequalities which arise from factors outside the agent's control, such as a person's natural and genetic abilities should be eliminated, but that inequalities or costs which arise from factors under the agent's control – assuming free and informed choices – should be accepted.

Methods
Advances in genomics and relevant examples are analyzed using the case-implication approach and the prior-principle approach to ethical reasoning.

Results
Genetic information enables us to understand better how one important factor which is clearly outside individual control – a person's genes – interacts with others to cause individual health outcomes. This has implications for social and individual responsibility for health. For example, insofar as compulsive gambling, obesity or familiar hypercholesterolemia are partly caused by factors beyond individual control, society has an obligation to fund health care for such groups. Health care systems and health insurance plans do not, on the other hand, have an obligation to reimburse the cost for e.g. statins to people with moderately raised levels of cholesterol before appropriate behavioral interventions have been tried. In addition, equal opportunity ethics provides a powerful argument against allowing genetic discrimination in the market for health insurance.

Conclusions
The implications of genomics for justice may be different in different health care systems. In European health care systems, new genetic knowledge might provide arguments for limited introduction of personal responsibility for health. In the US, genomic medicine might provide additional arguments in favour of a public health care system where society finances the treatment of health care problems which arise from genetic- and other factors outside individual control.

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Introduction

Genomic medicine will affect clinical practice and profoundly shape public health, as noted by several authors in this field (1-4). Genomics will also significantly affect our views of a just distribution of health and health care in society (4-9). It is commonly believed that society should ensure all individuals equal opportunities. Genomics provides information on genetic susceptibility to disease and possibilities for interventions which can fundamentally alter the design of fair health policies. The aim of this paper is to explore these implications of genomics from the perspective of equal opportunity ethics.

Equal opportunity ethics argues that all inequalities which arise from factors outside the agent's control in the social and the natural 'lottery', such as a person's natural and genetic abilities should be eliminated, but that inequalities or costs which arise from factors under the agent's control – assuming free and informed choices – should be accepted (10-21). Equal opportunity ethics can thus be seen as combining the principle of equality with the principle of responsibility. However, societies differ in how much weight they attach to these concerns. European welfare states have strongly promoted the principle of equality by securing universal access to health care, while the US has traditionally assigned more weight to the principle of responsibility and failed to promote universal access. The policy challenges of the new genomics can therefore be radically different and depend on the cultural and institutional context in which they arise.

Current health care policies deviate from the ideal of equal opportunity in two important ways. Many health care systems hold individuals responsible for too much by giving less priority to diseases such as obesity, mental illness and addiction which commonly, and in our opinion mistakenly, have been believed to be purely a result of individual behaviour. On the other hand, some health care systems and health insurance plans hold individuals responsible for very little, for example by reimbursing statins to people with moderately raised levels of cholesterol before appropriate non-medical interventions have been tried. It could be argued that the first type of deviation is more of a problem in the US, while the second type of problem is perhaps more common in European type of health care systems. Better genetic information could reduce both these information problems and enable us to implement policies which actually do equalize opportunities more. Better genetic information could, however, have the opposite effect, making it easier to discriminate against individuals with unfavourable genes, for instance in the market for health insurance.

Genomics will also have important implications for equal opportunity policies by providing the technology necessary for genetic interventions that could directly equalise individual opportunities. A prominent example is phenylketonuria – where simply providing a diet without phenyalanine is enough to prevent severe mental retardation (22). This technology, and prenatal diagnostics and gene replacement therapy in general, enable individuals to control factors which were previously beyond individual control. However, it also creates new challenges for equal opportunity policies which are aimed at giving individuals responsibility for their choices. We argue that it is important to have a good understanding of what it means to give individuals responsibility for their own health, in order to handle the new possibilities in a just manner.

Genetic information and social responsibility for health

A core question in political, legal and ethical debate is what society is obliged to do to help groups of disadvantaged people. How this question is answered typically depends on the extent to which the public at large believes that these groups are disadvantaged as a result of their own free and informed choices. In a society where the ideal of equal opportunity is the dominant ideal of justice, there is strong support for alleviating disadvantages which are seen as the result of factors beyond individual control, but there is less support for policies aimed at reducing inequalities which are seen as the result of controllable factors (23).

We will argue that some social policies towards disadvantaged groups are based on false beliefs about the causes of illness, with the result that individuals have been held responsible for too many health-related disadvantages. Scientific advances in medicine and social science can correct such misconceptions. Genetic information is particularly important in this respect because it enables us to understand better how one important factor which is clearly outside individual control – a person's genes – interacts with others to cause individual health outcomes.

Consider the case of compulsive gambling. Traditionally, public health care systems have not viewed the treatment of compulsive gamblers as their responsibility. This was presumably because it was commonly believed that a person can freely chose whether or not to gamble. Compulsive gambling is now gaining recognition as a significant public health issue (24). Recent research on the neurobiology of addiction suggests that genetic variation may partially underlie such behaviour (25). Thus, some individuals may be more susceptible to developing an addiction than others because of genetic factors beyond their control. If this

is correct, then society is obliged to do more to help compulsive gamblers in order to maintain equal opportunity. We predict that as the public becomes more aware of the genetic component behind compulsive behaviour, public opinion will change.

Consider also the more complex case of obesity, which according to the commonly used World Health Organization definition is "an accumulation of excess body fat, to such an extent that health might be impaired" (26). The idea that individuals are fully capable of controlling their obesity is still a common misconception, and probably part of an explanation for why this tremendous health problem in both the developed and the developing world has received little serious public health attention (27, 28). Genomics, however, together with other medical research, has demonstrated that there are a wide variety of contributing factors including genetics, family history, education, as well as diet (29). Although we do not know yet how large the genetic contribution is, there is obviously not a simple causal pathway from the choice of diet or the level of exercise to obesity. The recognition that genetic factors, as well as other factors clearly beyond individual control, are at work will probably change how the public views their obligations towards this disadvantaged group. Equal opportunity ethics require higher priority in the health system to measures that can prevent, treat or compensate for the high risks associated with obesity (30).

Genetic information and individual responsibility for health

A common misconception in equal opportunity ethics concerns what it means to hold someone responsible for their behavior. It is often assumed that, if a person is responsible for his or her behavior, then he or she should bear the costs of its consequences. However, equal opportunity ethics is not committed to this view. Because of differences in genes and other factors beyond their control, two individuals who engage in the same behaviour do not necessarily experience the same outcome. If we make individuals pay the actual cost of the consequences of their actions in such situations, ie, according to their individual outcomes, we also make them pay for costs caused by factors outside their control, ie, their genetic predisposition. Equal opportunity ethics implies that individuals who make the same choices should ideally bear the same costs regardless of the health outcome. It follows that society should not make individuals pay the whole cost of their treatment even where it appears that their illness results from their choices (31).

Genetic information is important in this context because it might provide information about how other factors interact with behaviour to determine health outcomes. Such

information would, for example, be important in determining whether or not co-payments are appropriate for the treatment of particular behaviour-related illnesses. Co-payments might be appropriate in cases where there is little individual variation in the consequences of a particular behaviour in terms of the need for treatment (32). However, co-payments are not appropriate when there are large individual variations in health outcomes between individuals who make the same choices, for instance, lung cancer in smokers. While smoking undoubtedly increases the probability of getting lung cancer, the increased risk depends on the genetic susceptibility of each individual and a host of other factors including chance. In this case, the best way to hold individuals responsible for their behaviour would be to levy a tax on tobacco products (31).

Genetic information will also, in some cases, provide information that enables us to distinguish between individuals who have a particular illness primarily due to individual choices and those whose illness derives primarily from factors beyond their control. To illustrate, consider the case of familiar hypercholesterolemia, which is associated with significantly increased risks of cardiovascular disease and premature death. Although many people have increased levels of serum cholesterol, patients with familiar hypercholesterolemia have significantly higher levels and will typically be detected on this basis. One type of familiar hypercholesterolemia involves mutations which change the degree of degradation of low density lipoprotein (LDL), a well-known risk factor for cardiovascular disease (33, 34). Individuals with this mutation have higher levels of cholesterol than others. The interesting ethical point is that those with this genetic polymorphism will have much higher levels of risk, compared to others, even if they make the same choices with respect to diet. Even without genetic testing, we are able to diagnose familiar hypercholesterolemia, and equal opportunity ethics provides a strong claim for securing this group the same health outcome as others who make similar life style choices. In practice, such equalization could take place by providing this group with free preventive treatment in the form of medical drugs (as is common policy in most countries), while introducing co-payment for low risk individuals who need such treatment due to life style choices. We leave aside here the practical and other ethical problems associated with implementing such a policy (31).

A similar argument arises in the case of obesity. Although genetic susceptibility for obesity is in most cases multifactorial (some genetic contribution combined with a complex set of environmental interactions), there exist some very rare types of monogenic obesity, probably associated with melanocortin 4 receptor mutations involved in the leptin regulation of food intake (26). Although we recognize that genetic factors may only rarely explain the

etiology of obesity, studies underway in this field, as well as in other fields such as cardiovascular disease and diabetes, may change the picture. Equal opportunity ethics would differentiate society's obligations to obese people who have inherited a strong genetic disposition for obesity. A just society should provide this group of people with the same opportunities in health outcomes as others in society.

Genetic information and market outcomes

A commonly expressed concern is that new genetic information will be used by market actors in ways which would harm particularly vulnerable groups, for example by denying them access to health insurance or by discrimination in employment (4). Political steps have been taken in many countries to avoid this development. By way of illustration, the US Senate passed the Genetic Information Discrimination Act of 2005 by a vote of 98 to 0. This prohibits the improper use of genetic information by health insurers and employers (35). There has been little resistance from market actors to this political development, which is probably because new genetic information has not, so far, been very effective in predicting common diseases. However, this may easily change if further progress is made in genetic research. One plausible scenario for the future is that market actors will lobby in favour of allowing some genetic discrimination in market transactions.

Equal opportunity ethics provides a powerful argument against allowing such genetic discrimination. New genetic information can be seen as lifting a veil of uncertainty about individual risk factors. In the market place this veil has ensured a certain measure of equalization by allowing pooling of risk between individuals with different genetic susceptibility. If genetic discrimination is allowed, individuals with high risk would be forced to pay higher premiums and there would be less equalization. Genetic discrimination would thus violate the core idea of equal opportunity ethics, namely that society as a whole should bear the consequences of factors which are beyond individual control.

Genetic interventions and responsibility

The possibility of genetic interventions is another aspect of genomics which may have important implications for equal opportunity policies. Implicit in the ideal of equal opportunity is the idea that we want to treat individuals *as if* they were identical with respect to factors outside their control (36, 37). The need for redistributive policies thus arises from

the fact that people differ with respect to their genetic makeup and other factors outside their control. Genetic interventions can potentially enable us to reduce such differences (8).

Genetic interventions might also create new choices and allow individuals to control factors that have been outside their control, as in the case of prenatal diagnostics and gene replacement therapy. Gene replacement therapy is a technique for inserting functioning genes into cells so that the necessary proteins or enzymes are produced. This is theoretically relevant for diseases such as phenylketonuria, Gaucher's disease, hypercholesterolemia, and diabetes. Today, gene replacement therapy is considered experimental and only a few cases of such trials have been published (38). However, it is easy to see that if the technique ever becomes successful, as it might in the case of gene or cell replacement therapy for type 1 diabetes, it will create new choices both for the individual and for society (39). A fundamental ethical question is what happens to society's obligations towards people who do not want to undergo this type of genetic intervention even if it is available. A naïve interpretation of individual responsibility would be that individuals should bear the full consequences of such a choice. This may imply that society no longer has an obligation to treat diseases caused by genetic deficiencies that could have been prevented by gene replacement therapy. This, however, is not implied by the equal opportunity approach. If society wants to give all individuals equal opportunities *not* to go through with gene therapy, for example, because such procedures are risky, everyone in society should share the cost of making this choice.

A less spectacular, but more common and pressing problem relates to choices following genetic testing of potential parents or the foetus. Typical examples are genetic testing and counselling for Tay-Sachs' disease, Huntington's disease and Down's syndrome. With widespread testing becoming the norm, rather than the special case, the pressure on prospective parents increases. Since it is now possible to collect prenatal information about the foetus, it is also possible to prevent the birth of a disabled child. If we believe that parents are responsible for the choice they have in this situation, what would such a responsibility imply? As in the case with gene therapy, it does not follow from this perspective that parents who decide to give birth to disabled children should be held responsible for the additional costs of bringing up a disabled child. Parents who give birth to a disabled child make the same choice in the ethically relevant sense as parents who decide to give birth to a child who is not disabled. Consequently, equal opportunity ethics would aim at equalizing the overall outcomes for all parents, which implies that society would have substantial obligations towards assisting the disabled child.

Concluding remarks

In this paper we argue that genetic information has had, and will continue to have, a profound effect on our views of a just distribution of health and health care in society. We have argued that genomics can provide us with information necessary to promote a society of equals. Lack of genetic information has led to health policies that in some cases hold people responsible for too much and in some cases hold them responsible for too little. The shift towards genomic medicine might thus not only improve clinical practice and public health, but also help us design fairer health policies. However, the implications of these changes will be different in different health care systems. In European health care systems, new genetic knowledge might provide arguments for limited introduction of personal responsibility for health. In the US, genomic medicine might provide additional arguments in favour of a public health care system where society finances the treatment of health care problems which arise from genetic- and other factors outside individual control.

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