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Genetics and Personal Responsibility for Health

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Abstract

Advances in genetic medicine may have implications for how we should think about personal responsibility for health, because they may show how it is possible to exert some control over risk factors that were previously thought as beyond the individual's control. Although we cannot control the genes that we are born with, we can often make decisions concerning genetic testing, disease prevention, and treatment. One might argue, therefore, that individuals should be treated as morally responsible for taking effective action in response to genetic risks factors, since genetically-based health risks are similar to other health risks. While this argument makes sense as an abstract, philosophical position, it is not a useful guide to public policy. Given these concerns, there is little society can or should do to encourage individuals to address their genetic risk factors, other than praising those who make prudent choices.

Keywords

genetics; moral responsibility; health; genetic testing; breast cancer; lifestyle; ethics

Angelina Jolie's public revelation on May 14, 2013 that she had a double mastectomy to prevent breast cancer provides a vivid illustration of the power of genetic testing (Jolie 2013). Earlier that year, Jolie had tested positive for mutations of the BRCA1 gene associated with a 60% lifetime risk of developing breast cancer and 40% lifetime risk of developing ovarian cancer (National Cancer Institute 2013). Jolie's mother died of breast cancer at age 56, and doctors estimated that Jolie's lifetime risk of developing breast cancer was about 87%, which is seven times higher than average woman's risk (Jolie 2013). Jolie did not say whether she will have her ovaries removed, but many women with BRCA1 or BRCA2 mutations choose this option (Jolie 2013). Other women who test positive for BRCA1 or BRCA mutations opt for less radical preventative measures, such as taking tamoxifen prophylactically or having more frequent mammograms. Jolie used genetic information to make a medical decision that she described as a "proactive" measure to reduce her breast cancer risk. In so doing, she took personal responsibility for her health.¹

¹It is worth noting that Jolie was in a privileged position with respect to her decision since she had access to best health care money can buy as well as social support. Other women who lack access to good health care, social support, and other resources may find it more difficult to take effective action to deal with their genetic test results.

For many years, genetic diseases were viewed as beyond the individual's control (Kitcher 1997). If you had the misfortune to be born with genes that predispose you to developing cancer, diabetes, high blood pressure, or many other diseases, there was not much you could do about it. Genetic medicine is rapidly challenging this assumption, however. As more genetic tests become available, it will be possible to test for genetic risk factors for many different diseases and take measures to prevent or treat them. Women who undergo BRCA1/BRCA2 testing can, like Jolie, use their results to exert some control over their health. Likewise, a person who tests positive for a gene associated with Type 2 diabetes could use that information to modify his or her diet or begin an exercise regimen (Prokopenko et al 2008). Someone who learns that they have a gene that predisposes them to alcoholism could use that information to decide to refrain from drinking alcoholic beverages (Wang et al 2012). Private companies, such as 23 and Me, now offer direct-to-consumer genetic testing for over 200 diseases and health conditions (23 and Me 2013). In the not too distant future, it will be possible to sequence an individual's entire genome for \$1000, which will exponentially expand the availability of genetic information with medical applications (Davies 2010).

As genetic medicine continues advance, it will become increasingly implausible to say that genetic diseases are completely beyond the individual's control. Bringing genetic diseases within the realm of the individual's control will allow people to live healthier lives than they would have otherwise, but also will likely place added pressure on people to undergo genetic testing and take steps to reduce their risks. These developments may also influence how we ought to think about personal responsibility for health, which could have significant policy implications.² This article will examine the impact of advances in genetics on the responsibility for health debate and argue that policies which hold individuals accountable for taking effective action in response to their genetically-based health risks have significant problems. Given these concerns, there is little society can or should do to encourage individuals to take effective action in response to their genetic risk factors, other than praising those who make prudent choices.

Responsibility for Health

Responsibility is an essential concept in morality and is closely linked to the concept of agency.³ A moral agent is an autonomous individual who is capable of understanding and following the dictates of morality (e.g. moral norms or rules). Moral agents can be held responsible for their actions and accountable for their conduct (Oshana 2002). To be accountable for one's conduct, one must a) be able to give a justification or explanation of the conduct to others; and b) face the consequences (e.g. rewards, punishments, praise, blame) related to the conduct. If a professional baseball player tests positive for a banned performance enhancing drug, then Major League Baseball (MLB) could hold him accountable by demanding that he explain the test result. If he has no satisfactory

²This article will focus on responsibility for one's own health, not responsibility for the health of others, such as children, parents, or siblings.

³Responsibility is also an important concept in law. This paper will focus on moral responsibility and will not draw any conclusions concerning legal responsibility.

explanation of the test result, MLB could administer a punishment, such as prohibiting him from playing baseball for a period of time.

Moral responsibility depends on casual responsibility: we can be held morally responsible only for those things over which we can exert some control.⁴ For example, if a strong wind causes a healthy tree in my yard to fall on my neighbor's house, I would not be morally responsible for the damage, because I have no control over the wind. However, if a moderate wind causes a rotten tree to fall on my neighbor's house and I knew (or should have known) that the tree was rotten but took no effective action to deal with it, then I would be at least partly morally responsible, because I had some control over the fate of the tree. My neighbor could blame me for allowing the tree to fall on his house and possibly seek legal redress.⁵

While causal responsibility is a condition for moral responsibility, moral responsibility is different from causal responsibility, because some outcomes that we cause may be morally excusable or justifiable. For example, accidentally killing a pedestrian who runs into the middle of traffic may be excusable and killing in self-defense may be justifiable (Oshana 1997). We may also excuse behaviors when the individual is not fully autonomous, due to age or mental disability. For example, children are not regarded as morally responsible until they develop the cognitive abilities and emotional maturity necessary for understanding and obeying moral norms.

When we claim that someone is responsible for their health, we are assuming that they have played a role in causing their own health. The degree of moral responsibility should correspond to the degree of casual responsibility. If an individual has played a major role in causing a disease or condition, then he or she would be largely responsible for their disease or condition. For example, an alcoholic might be held largely responsible for developing liver cirrhosis. If an individual has only played a minor role in causing a disease or condition, then he or she would only be partly responsible. For example, someone with significant hereditary risk factors for heart disease might only be partly responsible for developing this condition.

Determining the extent to which an individual is causally responsible for his or her own health is a complex affair, because many different causal factors, some within the individual's control and some not, impact health (World Health Organization 2002). Factors beyond the individual's control include genetics (e.g. disease susceptibilities) and the environment. Environmental factors that impact health include many different agents and conditions, such as: pollutants and toxins, radiation, weather, food, water, infectious diseases, culture, buildings, and infrastructure. Factors within the individual's control include various life choices, such as: occupation or work, risky behaviors, diet, exercise, smoking, alcohol and drug use, and sexual activity. Genetic, environmental, and lifestyle

⁴Determinists claim that all of our decisions and behaviors are caused by psychological or environmental factors beyond our control and that the notion of moral responsibility is therefore incoherent. In this article, I will assume that people can control some of their decisions and actions and that the notion of moral responsibility makes sense. See Dennett (1984) for further discussion of determinism and free will.

⁵Whether legal recourse would be available to my neighbor depends on the extent of my legal responsibility. A court might find that I acted negligently by not cutting down the rotten tree.

factors may also interact in complex ways. For example, developing Type II diabetes may depend on genetic susceptibility as well as environmental influences (e.g. food advertising) and life choices (e.g. overeating, not exercising).

While it may be difficult to determine in any particular case the precise role that an individual has played in causing his or her own health, few people would deny that most people are at least partly causally responsible for their own health. The more controversial issue is to what extent (if any) individuals should be viewed as morally responsible for their own health (Wikler 1987, Minkler 1999, Callahan et al 2000, Cappelen and Norheim 2005, Cappelen and Norheim 2006, Resnik 2007). Policy proposals (some of which have been implemented and others only debated) for holding individuals accountable for their health include (Morreim 2000, Blacksher 2008, Bayer 2008, Callahan 2013):

- Imposing high taxes on cigarettes, soft drinks, and other products that pose health risks;
- Charging higher health insurance rates for smokers or obese individuals;
- Giving individuals who meet specific wellness targets a discount on health insurance;
- Not providing insurance coverage for minor health problems that are clearly the individual's fault;
- Refusing to hire smokers or obese individuals;
- Giving lower priority to alcoholics on waiting lists for liver transplants;
- Refusing to treat heart or lung disease in smokers until they quit;
- Stigmatizing people with lifestyle-related diseases.

There are two basic arguments for treating individuals as responsible for their own health: a utilitarian argument and a fairness argument (Wikler 1987, Minkler 1999, Callahan et al 2000, Cappelen and Norheim 2005, Cappelen and Norheim 2006, Resnik 2007, Sharkey and Gillam 2010). According to the utilitarian argument, individuals should be regarded as at least partly responsible for their own health in order to motivate them to make choices that reduce their risk of disease. For example, charging smokers higher insurance rates will encourage them to stop smoking. Making individuals accountable for their health-related behaviors benefits society by improving the health of the population and reducing health care costs (Minkler 1999). According to the fairness argument, it is fair to regard individuals as responsible for their own health to the extent that they have caused their own problems. For example, it would be fair to require individuals to pay for tattoo removal and unfair to ask others to pay for it (Cappelen and Norheim 2005). It would also fair, according to this argument, to give individuals with alcoholic liver cirrhosis lower priority on transplant waiting lists, because they have damaged their livers.

Critics of regarding individuals as morally responsible for their own health have objected to these arguments as well as specific policy proposals. One of the most significant objections is that a number of different factors outside of the individual's control, such as genetics the environment influence the risk of disease (Minkler 1999). Charging obese individuals higher

health insurance rates may not be fair to people with genes that slow their metabolism and cause them to gain weight. A second, related, objection is that it can be difficult to implement some of the policies that hold individuals accountable for their contribution to their own health, because diseases result from a complex interplay between factors, many of which are outside of the individual's control (Callahan et al 2000). For example, fairness would require that if obese individuals are charged higher insurance rates, these rates should reflect the individual's contribution to their own obesity, which can be difficult to estimate. A third objection is that refusing to treat individuals with lifestyle-related diseases runs counter to the medical profession's obligation to aid the sick and society's obligation to help people in need (Callahan et al 2000). It would be unprofessional and inhumane to not treat a smoker with lung cancer or an alcoholic with liver disease. A final objection is that stigmatizing people with lifestyle-related diseases is a form of blaming the sick that causes unnecessary psychological suffering without significantly impacting behavior (Wikler 1987, Minkler 1999).

Since the arguments for and against holding individuals responsible for their own health have been discussed elsewhere, I will not examine them in depth here (see Minkler 1999, Callahan et al 2000). I will assume, however, that it makes sense to hold individuals at least partly responsible for their own health in some cases. In the remainder of this article, I will focus on how advancements in genetic medicine may impact the responsibility for health debate.

Genetics and Responsibility for Health

Advancements in our understanding of the genetic basis of disease may impact the responsibility for health debate in two different ways (Novas and Rose 2000, Weiner 2011). Research on genetic susceptibilities to disease could weaken the rationale for holding individuals morally responsible for their own health by providing evidence that the individual's health results from factors beyond his or her control. For example, research on the genetics of food metabolism might undercut the argument that obese people should be held responsible for their condition by showing that factors outside control of the individual cause obesity (Cappelen et al 2008). Conversely, research might strengthen the rationale for holding individuals responsible for their health by showing how it is possible to effective action in response to genetic risks. For example, although Jolie had no control over her genetic susceptibility to cancer, she had some control over how she responded to this risk, and she took steps to minimize her it.

While Jolie's case represents a triumph of genetic medicine in the service of public health, advancements in genetic medicine raise some novel questions concerning personal responsibility for health. Suppose Jolie had decided to ignore the results and developed breast cancer. Should we blame her for not taking effective action to reduce her disease risk? Do those who have a family history of breast cancer have a moral obligation to be tested for breast cancer genes so they can take effective action to reduce their risk of developing this disease?⁶

These are challenging questions to address because for many years genetic diseases have been viewed as largely beyond the individual's control. Even though individuals cannot control the genes they are born with, they may be able to control how they respond to their genetic risk factors, because they can decide whether to have genetic tests and what to do with their results. Although some diseases with a genetic basis, such as Huntington's disease or Alzheimer's dementia, cannot be effectively prevented or treated currently, others, such as familial hypercholesterolemia, Type 2 diabetes, and some types of cancer, can be. Moreover, the number of genetic diseases that can be effectively prevented or treated is likely to continue to increase as medical science advances.

The main argument for regarding individuals as morally responsible for taking effective action to in response to their genetically-related health risks, which I will call the genetic responsibility argument, can be stated as follows:

1. We should be held morally responsible for taking effective action to reduce significant health risks within our control.
2. Some significant health risks related to genetic susceptibilities to disease are within our control.
3. Therefore, we should be held morally responsible for taking effective action to reduce significant health risks related to genetic susceptibilities to disease that are within our control.

Support for the genetic responsibility argument can be gained by comparing risks related to genetic susceptibilities to other health risks. If a smoker should be treated as morally responsible for quitting smoking to avoid lung cancer and emphysema, then a person who tests positive for genetic risk factors for breast cancer should be treated as morally responsible for taking effective action to prevent disease, to the extent that she has access to effective therapies. Likewise, a person with a family history of breast cancer who forgoes an affordable test for breast cancer genes should be treated as morally responsible for failing to obtain information needed to take effective action. While the genetic responsibility argument has considerable merit, it faces a significant objection that I will call the fairness objection. According to this objection, it would be unfair to hold us morally responsible for adverse health outcomes related to our genetic susceptibilities because we do not choose our genes. Genetic risks are different from other health risks.

While it might be fair to hold a smoker responsible for developing lung cancer, it would be unfair to hold a woman who tests positive for BRCA1 or BRCA2 mutations responsible for developing breast cancer if she takes no preventive action, because she did not choose to have these genes, whereas the smoker chose to smoke. The woman with BRCA mutations has found herself in an unfortunate situation and decided to do nothing to minimize her risks, while the smoker has willingly assumed risks. It would be unfair to punish a woman with BRCA mutations for not addressing her risks or to otherwise hold her accountable for her bad genetic luck.

⁶By "effective action" I mean measures to reduce the risk of disease, such as prevention or treatment. Obtaining genetic tests results is a necessary part of taking effective action, since one cannot take effective action to reduce a risk if one does not know what the risk is.

In response to this objection, one might argue that while fairness issues should be considered, we are still responsible for taking effective measures to minimize health risks we can control, even when we have not caused those risks. Fairness concerns may modify, but do not negate, moral responsibilities. For example, no one has control over solar radiation, which is a risk factor for skin cancer (Centers for Disease Control and Prevention 2013). However, we can control our exposure to solar radiation by wearing protective clothing, using sunscreens, or avoiding outdoor activity during the time of day when solar radiation is most intense. We would say that a person who knowingly ignores advice to minimize skin cancer risk and develops this disease is at least partly responsible for this adverse health outcome. It would be fair to hold the person at least partly responsible for developing skin cancer, even though he has no control over the sun.

Defenders of the fairness objection might challenge this example on the grounds that we often cannot take effective action to minimize health risks due to genetic or environmental factors. Agricultural workers may not be able to avoid prolonged exposure to the sun, and people who live in areas with high levels of air pollutants may not be able to avoid breathing contaminated air. Likewise, people with genes for Huntington's disease or Alzheimer's dementia cannot avoid developing these conditions. It would be unfair to hold such people morally responsible for minimizing environmental or genetic risks they cannot control.

This is a reasonable point. If we cannot take effective measures to minimize our health related risks, then it would be unfair to hold us responsible for adverse health outcomes related to those risks. Thus, if there are no effective ways of addressing risks due to genetic susceptibilities, then we should not be held responsible for diseases we develop as a result of those susceptibilities. However, the genetic responsibility argument focuses on risks that we can control, not on those that are beyond our control. If we can take effective measures to reduce significant risks related to genetic susceptibilities, then we are responsible for doing so.⁷ While there are currently no effective ways of preventing or treating some genetic diseases, such as Huntington's disease or Alzheimer's dementia, there are effective measures for preventing or treating many others diseases. We are responsible for taking effective action to reduce the significant genetic risks that we can control, not the ones that are beyond our ability to control.

Defenders of the fairness objection might also contend that it would be unfair to hold all people equally responsible for the same health risks, because people differ in their ability to control risks, due differences in access to health care, education, social support, or other factors. It would be unfair to hold someone responsible for addressing a controllable genetic risk if that person cannot afford genetic tests and preventative measures or treatments, or lacks social support. Not everyone has the same social and economic advantages as Angelina Jolie. While it might be fair to hold Jolie morally responsible for addressing her genetic risks, it would unfair to hold women responsible who have far fewer advantages.

⁷Responsibility should be a function of the significance of the risk we face: the greater the risk, the greater our responsibilities. Some genetic risks may be so small that we should not be expected to pay attention to them.

This is also a reasonable point that places some practical limitations on the genetic responsibility argument but does not defeat it entirely. While it would be unfair to hold people who lack access to testing, prevention, or treatment morally responsible for addressing their genetic susceptibilities, it would be fair to hold those responsible who do. Policies that hold individuals accountable for taking effective action to address their genetic risk factors need take social, economic, cultural, and other circumstances into consideration.

Genetic Responsibility as Public Policy

While the genetic responsibility argument makes sense as an abstract, philosophical position, it is not a useful guide to public policy, because there are enormous practical challenges with implementing policies that hold people accountable for managing their genetically-related health risks. To appreciate this point, it will be useful to consider some possible strategies for holding individuals accountable for their genetically-related health risks.

The most straightforward way of holding individual accountable would be through health insurance and employment. Insurance companies could require individuals to undergo genetics tests for a variety of conditions. Individuals who test positive for genetic risk factors could be denied coverage or charged higher rates if they do nothing to address those factors. Employers could use the same strategy to encourage workers to deal with their genetic risks. Employers could refuse to hire individuals who refuse to submit to genetic tests or choose not to address their genetic risks.

The trouble with this strategy is that health insurance and employment discrimination based on genetic risk is illegal in the US and many other countries. One of the main reasons why countries have adopted these laws is that many people regard genetic discrimination as unfair to individuals born with genetic conditions that they did not choose (Hudson et al 2008). In 2008, the US enacted the Genetic Information Nondiscrimination Act (GINA), a federal law that prohibits health insurers from using the results of genetic tests to determine eligibility or insurance rates, and prohibits employers with 15 or more employees from using the results of genetic tests to make employment decisions. GINA also makes it illegal for health insurers or employers to require individuals to undergo genetic testing (Genetic Nondiscrimination Act 2008). GINA does not prohibit employers or insurers from encouraging individuals to undergo genetic testing and it does not apply to life insurance or long-term disability insurance. The strength of the law is still indeterminate because it has not been well-tested by the courts (Hudson et al 2008, Levin 2013). Australia, Canada, New Zealand, and many European countries have statutes that ban genetic discrimination or constitutional provisions that imply that genetic discrimination is unlawful. In the future, others countries will likely adopt laws that prohibit genetic discrimination (Otlowski et al 2012).

Since it would be illegal in the US and many other countries to use health insurance and employment to hold individuals accountable for taking effective action to deal with the genetic risk factors, how could society hold individuals accountable for addressing their

genetic risks? Other options would include taxation, organ transplant de-prioritization, social stigma, and moral praise.

It is difficult to even imagine how a government could use taxation to motivate individuals to address their genetic risks factors. One way to do this would be to require citizens to provide genetic tests results to the government on their tax forms and report how they have addressed their risk factors. A tax rate table could be used to adjust rates accordingly. This would be a problematic proposal, because most people would not want to submit this private information to the government, even if it meant that they could lower their taxes. Also, people would be tempted to lie about what they have done to address their genetic risks factors.

Giving people who do not address their genetic risk factors lower priority on organ donation waiting lists would be similar to giving alcoholics lower priority on waiting lists for receiving new livers. Genetic factors play an important role in some types of organ failure. Individuals with Type 1 and Type 2 diabetes can develop kidney failure or become blind if their disease is not well-managed. One could argue that people with diabetes who do not take effective action to address genetic risk factors related to their disease should receive lower priority on waiting lists for receiving organs.

A key problem with this proposal is that lifestyle factors and health care choices play a major role in disease progression and disease impact. Type 1 diabetics cannot control whether they develop the disease, but they can control whether they take their medications as directed and watch their diet. For Type 2 diabetics, diet and exercise play an important role in preventing the disease. Diet, exercise, and medication compliance also are important in management of the disease once it develops. Since lifestyle factors and health care choices play a major role in diabetes progression and impact, health accountability policies would do best to focus on encouraging diabetics or pre-diabetics to make wise lifestyle and health care choices. Punishing people for not undergoing genetic tests or not responding effectively to the results of genetic tests probably would not have much of an impact on diabetes management. This same point would also apply to other genetically-based diseases that lead to organ failure.

What about pursuing a policy of social stigma? Individuals who fail to take effective action to deal with their genetic risks could be stigmatized, much in the way that obese individuals, smokers, and others are stigmatized. As more genetic tests become available, the social pressure to deal with genetic risks would increase, which would hold individuals accountable and encourage them to take effective action in response to their genetic risk factors.

As mentioned earlier, there are ethical problems with using social stigma to hold individuals accountable for their health. While social stigma has probably helped to reduce the prevalence of smoking, it may not help to reduce the prevalence of other lifestyle diseases and conditions, such as obesity, HIV/AIDS, and substance abuse, and may have a negative public health impact (Stuber et al 2008, Puhl and Heuer 2010). Obesity has been stigmatized for many years, but there is little evidence that stigma actually reduces the prevalence of

obesity. Moreover, stigma can lead to psychological stress among those who are obese. Obesity stigma is a risk factor for depression, low self-esteem, and body dissatisfaction. Psychological distress can have a negative impact on physical health. Stigma can also lead to discrimination and prejudice, which may negatively affect access to health care, employment, and personal relationships (Puhl and Heuer 2010). Moreover, stigmatizing people who do not take effective action to address their genetic risk factors may be unfair to those who lack access to genetic testing, health care, and other resources (see the fairness objection above). Thus, social stigma is probably not an appropriate strategy for holding people accountable for dealing with their genetic risks.

Although social stigma is not a productive strategy for holding individuals accountable for taking effective action in response to their genetic risk factors, praise might be. This option would involve making a concerted effort to praise individuals, such as Jolie, who take effective action to address their genetic risk factors. These individuals could be held out as an example for others to follow. This option would involve positive, not negative reinforcement. The only potential problem with this option is that it might lead to stigma if care is not taken to avoid blaming people who do not address their genetic risk factors. Since praise and blame are opposite sides of moral evaluation, it may be difficult to pursue a strategy that only involves praise without succumbing to the temptation to blame.

Conclusion

Advancements in our understanding of the genetic basis of disease may impact the responsibility for health debate by showing how it is possible for individuals to minimize health risks related to their genetic susceptibilities. One might argue, therefore, that individuals should be treated as morally responsible for taking effective action in response to genetic risk factors, since genetically-based risks are similar to other health risks. While this argument makes sense as an abstract, philosophical position, it is not a useful guide to public policy because there are serious practical problems with holding individuals accountable for taking effective action to address their genetically-based health risks. Policies that amount to genetic discrimination in health insurance or employment would be illegal in many countries. Taxation and de-prioritization for organ transplants both face significant practical problems, and stigmatizing people who fail to address their genetic risk factors could do more harm than good. Given these concerns, there is little society can or should do to encourage individuals to take effective action in response to their genetic risk factors, other than praising those who, like Jolie, make commendable choices. While praising those who take effective action to address genetic risks is a useful way of holding individuals responsible, care should be taken to ensure that this strategy does not lead to stigmatization.

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