CLINICAL ETHICS

Ethical issues in predictive genetic testing: a public health perspective

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As a result of the increase in genetic testing and the fear of discrimination by insurance companies, employers, and society as a result of genetic testing, the disciplines of ethics, public health, and genetics have converged. Whether relatives of someone with a positive predictive genetic test should be notified of the results and risks is a matter urgently in need of debate. Such a debate must encompass the moral and ethical obligations of the diagnosing physician and the patient. The decision to inform or not will vary depending on what moral theory is used. Utilising the utilitarian and libertarian theories produces different outcomes. The principles of justice and non-maleficence will also play an important role in the decision.

Genetic testing is a relatively new and rapidly emerging field; yet, public health has been involved in public policies and practices involving genetic testing for conditions such as phenylketonuria and sickle cell disease for some time.[1] This article will address earlier and currently emerging issues related to public health, primary care practice, and genetic testing. A number of cases from the literature are reviewed, as well as the moral theories that have dominated public health and medical practice in the United States. Suggestions are made regarding ethics education for public health and medical practitioners, which specifically relate to the emerging ethical dilemmas posed by the growing availability of predictive genetic tests.

There are three forms of genetic testing: diagnostic, carrier, and predictive testing. Diagnostic testing involves identifying current disease states. This includes prenatal and newborn screening—the most common forms of genetic testing. Carrier testing determines whether an individual carries a certain genetic trait. Each person's genetic traits are comprised of two chromosomes: one inherited from his/her mother and one from his/her father. If a genetic disorder is dominant, the disease characteristics will be expressed when a person has one abnormal chromosome. If a genetic disorder is recessive, the disease characteristics are present when the individual has two abnormal chromosomes. If the disorder is X-linked, the disease characteristics will be present in males. The third type of genetic testing, predictive testing, is used to determine whether a person has a genetic mutation that will lead to a late onset disorder. This type of testing is usually conducted in otherwise healthy individuals with a positive family history and no symptoms of disease.[2 3] Examples of disorders for which genetic tests are available are Huntington's disease, cystic fibrosis, breast cancer, Down's syndrome, sickle cell anaemia, and phenylketonuria.[1 3]

MORAL AND ETHICAL IMPLICATIONS

Genetic discrimination has moral and ethical implications. The debate over these issues has historical roots. In this article we examine the moral and ethical implications of genetic testing and potential discrimination from perspectives that are dominant in the US healthcare system. In the early to mid 1900s individuals in the US who were continually ill or mentally retarded were involuntarily sterilised. One example of mandatory sterilisation in the US occurred in 1927 when Justice Oliver Wendell Holmes Jr, a well known judge, ruled in the *Buck v Bell* case in favour of mandatory sterilisation of Carrie Buck. Carrie Buck, her mother, and her seven month old daughter were labelled by the court as feebleminded. This ruling upheld Virginia's 1924 eugenic sterilisation law. Approximately 60 000 more sterilisation procedures followed throughout the US.[4] The Norplant contraceptive device received attention in the 1990s when judges in several states gave women convicted of child abuse a choice between serving time in jail or using Norplant. The American Medical Association condemned this form of coercion for infringing upon a person's reproductive rights and their right to refuse medical treatment.[5]

Genetic discrimination continued until the 1970s, when several states in the US required mandatory testing for sickle cell disease among African Americans.[2 6] Because sickle cell disease is a recessive trait, carriers of the disease were identified and then notified of the risks of having children with another carrier. African American children were required to undergo mandatory testing before entering school. Having sickle cell anaemia or being a carrier did not prevent a child from entering school. Refusal to participate in genetic testing did. The African American community, bioethicists, lawyers, and the medical profession viewed this as discrimination because other populations were not targeted for other possibly debilitating diseases. Legislation was passed granting money to fund sickle cell programmes in states with voluntary testing.

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Abbreviations: ADPKD, autosomal dominant polycystic kidney disease; HIPAA, Health Insurance Portability and Accountability Act; NTD, neural tube defects

This, in effect, overturned mandatory testing requirements.[6] Sickle cell disease testing is now offered as part of newborn screening, not limited to African Americans.

Americans feared that the development of genetic tests and the enactment of mandatory testing would decrease individual rights to privacy and lead to discrimination. It was realised that insurance companies could require testing and either refuse healthcare coverage, decrease benefits, or increase premiums. A study of members of genetic support groups revealed that 22% of respondents felt they had been refused health insurance.[7] Also, on the basis of predictive genetic testing, employers could deny employment to individuals at risk of becoming debilitated or who were likely to require costly health insurance and sick time benefits. In 1995, the Equal Employment Opportunity Commission issued guidelines stating that individuals who thought they had been discriminated against by an employer because of predictive genetic testing had the right to sue that employer. Additionally, the Health Insurance Portability and Accountability Act (HIPAA), enacted in 1996, prevented insurance companies from denying health care based on predictive testing for individuals transferring from one plan to another.[6] Despite such protections, a survey of members of the National Society of Genetic Counselors Special Interest Group in Cancer revealed that 68% of respondents who would undergo genetic testing would not bill their insurance company and 26% would use an alias. Reasons for not billing their insurance company included fear of genetic discrimination; fear that future insurability might be jeopardised; fear of discrimination against their children, and fear that existing laws were not adequate to protect them against discrimination.[8]

An example of genetic discrimination in the workplace occurred in 2000 at the Burlington Northern Santa Fe Railroad Company. Employees who filed claims and sought medical attention for carpal tunnel syndrome were required to submit blood samples. The samples were subjected to genetic testing to identify a genetic defect that predisposes an individual to nerve injury and forms of carpal tunnel syndrome. The US Equal Employment Opportunity Commission filed suit against the company for defying the Americans with Disability Act. The case was settled in May 2002 for $2.2 million.[9 10]

ETHICS, PUBLIC HEALTH, AND GENETICS

Since the debate about ethical issues surrounding genetic testing has gained momentum, the concerns of ethics, public health, and genetics have converged. Public health practitioners are tasked with identifying possible exposures and recommending testing for communicable diseases that are reportable conditions. If genetic disorders become reportable conditions due to the expansion of mandatory screening, public health practitioners could be faced with issues of disclosure. Lachman—for example, has described a scenario in which widespread immunologic genotyping would be required to reduce the transmission of global, drug resistant infections.[11] It would be expected that most mandatory testing would be provided within the private sector. However, the public health system retains responsibility for confidentiality and the effectiveness of genetic screening conducted ''under public health auspices''.[12] Holtzman cites an Institute of Medicine committee recommendation that newborn screening should only be conducted for conditions where the newborns themselves stand to benefit from the information gained, and not for predictive guidance for future pregnancies.[13] This is consistent with the public health doctrine of ''*parens patriae*, where the state acts to protect children against future disease''.[12] As population genetic screening expands from the newborn arena to adult onset conditions, there will also be a role for the public health system in the provision of genetic testing to needy segments of the population, and in the publicising of such campaigns.[14 15]

An example of a public health intervention occurred in south Texas in response to a cluster of neural tube defects (NTD) in 1991. A state wide folic acid and NTD prevention campaign was funded by the March of Dimes, and an NTD intervention project was piloted in west Texas and a Texas Mexico Border States Birth Defects Project piloted in Nuevo Laredo, Mexico, and Laredo, Texas.[16] The American College of Medical Genetics, the American College of Obstetricians, and the National Institute of Medicine provided an example of public intervention, this time for cystic fibrosis, when, at a consensus conference in 1997, they recommended that non-Jewish whites and Ashkenazi Jews be offered cystic fibrosis carrier screening, that it be made available to other ethnic and racial groups, and that information regarding the risks and detectability within those two groups be made available.[17] It is important to note that this was a recommendation for population screening of a voluntary, rather than mandatory, nature.

The idea that genetic testing is different from testing for other disorders is termed ''genetic exceptionalism''.[18] Genetic information is private and is directly related to an individual's identity. Not only is confidentiality an issue for health care, insurance coverage, and employment, but information from a genetic test can affect an entire family. If the disorder is either genetically dominant or carried by an individual, that person's parents, children, brothers, sisters, and even extended family may also be affected. Furthermore, a person may make life altering decisions based on the results of a genetic test.[3] Disclosure of genetic test results can be critical in all aspects of an individual's life.

Once a genetic disorder is discovered, the question then arises as to who should counsel the patient and/or family, and how the patient and/or family should be counselled. More and more often primary care physicians are serving as counsellors as the prevalence of genetic testing increases. However, even though the primary care physician is knowledgeable about the patient, their socioeconomic background, and personal attitudes, he/she may not be the best person to provide genetic counselling. It is not necessarily the case that the majority of primary care physicians are trained in medical genetics, diagnostic testing, and genetic counselling.[19] Yet, they have the greatest contact with patients and are likely to be the first provider asked about genetic testing. In a survey of physician knowledge and attitudes toward genetic testing, 95% of the physicians who responded felt it was the physician's responsibility to counsel patients. However, respondents reported their knowledge of genetics and genetic testing as either fair or poor.[20] Physicians may also work with, or refer to, professionals trained to conduct genetic counselling in a non-directive manner. Non-directive counselling upholds individual autonomy and allows the patient to make informed decisions voluntarily.[2 3]

Considerable debate surrounds the moral and ethical issues regarding persons who have undergone predictive genetic testing. One question of particular interest for this essay is whether or not family members should be informed of the test results. What are the moral obligations of the patient and the physician? Should someone diagnosed with a genetic disorder inform his/her family they may be at risk? Should the physician who has diagnosed the patient inform the family of the disorder and recommend testing? The answers to these questions are not easy and will vary depending on who is asked and what moral theory is used. The answers may also depend on other factors, such as the severity of the disorder.

UTILITARIAN PERSPECTIVE

Two moral theories to consider when answering the above questions are utilitarianism and libertarianism. Utilitarians believe moral decisions should be decided by calculating a burden/benefit ratio from a societal viewpoint. This perspective promotes the good of society over that of the individual. Factors taken into consideration when calculating total happiness include intensity, duration, certainty, propinquity, fecundity, purity, and extent.[2] If there are multiple people at risk, they should be informed. Informing at risk family members may decrease the *intensity* of pain for them through medical intervention; decrease the *duration* of symptoms through medical intervention; decrease the probability pain will occur *(certainty)*; delay the onset of the symptoms *(propinquity)*; increase the quality of life *(purity)* through adequate planning and lifestyle changes, and prevent the passing on of the disorder *(extent)*. This allows other members of society to be screened and make decisions that affect their families. The information could dissuade individuals from having children and passing on the genetic defect. Knowing of a disorder or preventing the passing of a genetic disorder by a couple deciding not to have children could save large amounts of money for treatments often paid for by society. The orientation of public health professionals toward population health has led to the application of the utilitarian perspective in the case of cystic fibrosis screening in the United States and thalassaemia screening in other countries,[21] but as the NTD example illustrates, such screening can also involve decisions about resource sharing. A communitarian perspective would place emphasis on the moral values of a defined community. Instead of resting solely on a calculus of burden/benefit for society, decisions are additionally founded on community norms, which can involve solidaristic principles.[22] Predictive testing of highly penetrant conditions is often a decision for the individual or family to make. As public health undertakes screening for more ubiquitous, less penetrant conditions, including chronic disease, decisions regarding programme implementation and disclosure policy can be expected to move in this ethical direction.

LIBERTARIAN PERSPECTIVE

Libertarians believe personal autonomy has the highest moral value. Each person has the right to make his/her own informed decisions. Individuals have the right to privacy, freedom of speech, and freedom from harassment.[2] Autonomy also suggests each person has the right to make an informed decision with adequate information and counselling. It is up to the individual to understand his/her disorder and make the choice to inform family members.[23] Additionally, there is trust between the physician and the patient. Physicians are traditionally expected to uphold patient privacy rights except in cases of mandatory reporting. Breaking the trust inherent in the patient/physician relationship could have devastating effects.

In matters of public health, liberty rights are often in conflict with the utilitarian perspective. The expectation exists that individuals will consent to testing not just for their own good but for the sake of their family and society as well. Also social stigmatism is attached to genetic disorders. Individuals diagnosed with a genetic disorder are often discriminated against and harassed by other members of society or even family and friends. Libertarians believe people have the right to live without such fear, discrimination, and social stigmatism.

For family members, there is also a right to not know. Family members may not want to know about their risk for a genetic disorder. Since genetic testing can cause a person to make life altering decisions, a person may live a happier life if he/she does not know. A person may restrict his/her life by not marrying, not having children, or not making certain career choices, leading to frustration and isolation.[3] The right not to know is supported by the principle of non-maleficence. A libertarian would conclude that each person has a right to be happy and make choices without being influenced by physicians, counsellors, and other members of society. Risk communication in the medical and public health contexts can be viewed as acceptable, but the ultimate decision is up to the patient. On the other hand, family members may view their rights differently. They may feel they have the right to know about their risk in order to be able to make fully informed decisions. This is where the physician may have to choose between the liberty rights of the patient and those of the patient's family members.

JUSTICE PRINCIPLE

The principle of justice is a pre-eminent consideration for public health professionals and also comes into play for family members at risk. Several theories of justice support the position that each person has the right to receive basic social goods such as medical treatment. If a person does not know he/she is predisposed to a genetic disorder, he/she does not have the information necessary to seek available treatments. The physician is always at the centre of the debate as to whether to inform family members of their risk. The physician is not only dedicated to protecting the confidentiality of patients, but also to the concept of doing no harm. If the physician does not inform family members, who together with their future children might themselves be at an increased risk for a genetic disorder, the principle of non-maleficence may be being violated. The physician's decision not to inform family members simply removes any possibility of delaying or ameliorating the onset of symptoms.[2] Consequently, the public policy function of public health may need to resolve these countervailing interests of individuals.

CASE PRESENTATION

Kielstein and Hans-Martin give a case example of a 55 year old female dialysis patient who was identified as a carrier of a dominant genetic disorder: autosomal dominant polycystic kidney disease (ADPKD). She had four sons who underwent screening and were identified as carriers. One of her sons was 32 years old and the father of a six year old when he first developed symptoms of ADPKD. He committed suicide. Another son, who was 30 years old, divorced his wife and sold their home to keep from burdening her or planning a family. He did not have problems until he was 54. A third son was 25 and left his fiancée for the same reason. He later died from another cause without having ever developed symptoms. The fourth son was 21 when identified as a carrier of ADPKD. He quit school and took a good paying job to live life to the fullest. He also never married. At the time of the article's publication, he was 42 and had never experienced symptoms.[23] This family demonstrates how knowing of a genetic disorder causes people to make life altering decisions.

This example illustrates elements of both utilitarianism and libertarianism. There are several critical points in the case described above that pose challenges both for families and the larger society, and which warrant ethical consideration. The second son, had he not divorced, would have exposed his family to the various costs resulting from kidney failure beyond age 54, and the eventual need for dialysis or transplant. This could have significantly burdened his wife, and clearly played into the calculus of his decision to leave. In forgoing a family, he avoided giving rise to children being born with a 50% chance of having the very same condition with its associated costs. The regrettable suicide of the first

son, in a raw utilitarian sense, removed the cost of a single dialysis or transplant from society. There are countervailing utilitarian considerations, such as years of gainful employment lost and the effect on their wives. A physician or a genetic counsellor might offer a clear explanation of the decisions, but nonetheless both would eventually reveal a type of utilitarian reasoning operating in the final decisions being made. The rarer, recessive form of polycystic kidney disease appears in the neonatal period, and, for those who survive, can result in insidious renal failure during childhood. Utilitarian considerations have also formed the basis of prenatal screening protocols for conditions that are likely to result in early childhood fatality or which result in severe or disabling childhood illness.[24]

The sons' decisions could not have been made if the family members had not been informed. In the making of these decisions, however, they demonstrated the use of the libertarian point of view, which states that each person has the right to make an informed decision. Each family member was allowed the opportunity to make the decision he felt was best. Though ethical decision making need not always translate into legal action, physician failure to warn of the possibility of the transmission of an adult onset, genetically associated condition, such as familial cancer, has resulted in lawsuits.[25] In these instances the daughters were robbed of the opportunity to seek testing for what eventually manifested as full blown disease.

On the other hand, each family member had the right not to know. If they had not known about the disorder, they might have lived much happier lives. This is certainly so for the son who committed suicide. Also, the sons who left family members and the one who committed suicide took away the personal liberties of their families to decide what was best.

Finally, it should not be forgotten that the decision to make dialysis machines available—for example, in the case of the 55 year old mother—is a societal one, as is the system developed to allocate transplant organs such as kidneys. Medicaid and insurance decisions on how much to allocate for newborn screening follow up likewise take place in the context of competing societal resources. As public health begins to shift from predictive to prophylactic or preventive genetic testing for middle to late onset conditions, communitarian considerations about how much members of society are willing to share for mutual benefit will also come into play. This is particularly true as a combined medical/public health approach concentrates increasingly on preventing disease manifestation through childhood and adult interventions.[14 26] Although not as frequent as cancer and heart disease, the condition in this example, ADPKD, is the most frequent form of hereditary renal disease, and thus deserves ethical scrutiny at the family and population levels.

AN EXISTING BALANCE

Modell and Citrin suggest there should be a balance between utilitarian and libertarian interests with regard to genetic testing. They propose several ethical considerations be examined when making moral decisions. These include respect for privacy; autonomy; personal best interest; responsibility for the genetic health of future children; maximising social best interest/minimising serious social harm; the reproductive liberty of individuals; genetic justice; cost effectiveness; solidarity/mutual aid, and respect for difference.[1] These considerations take into account the benefits to the individual *and* society so that benefits to both parties can be maximised and harmful effects to both parties minimised.

The above case illustrates, especially for the son who committed suicide, the harms of being informed of ADPKD. Benefits can, however, accrue from this information. Preventive actions could be taken by the person informed of this genetic condition, specifically avoidance of contact sports and lifestyle changes to prevent hypertension.[23] For conditions for which there is neither effective prevention nor intervention, the harms from disclosure would potentially be much greater.

In the discussion of the case, the authors discuss the duty of the provider to inform and the autonomy of the patient.[23] A World Health Organization 1998 guideline emphasises the right of the provider to make direct contact with the affected relatives.[23] The authors stated, however, that they preferred an interactive dialogue model of counselling where the provider unambiguously directs the patient to share the information. They argue that if the information has strong potential benefits to the relatives, and the provider's advice to inform the relatives is not heeded, then the provider has a moral duty to inform the relatives.

CONCLUSION

Deciding between the libertarian and the utilitarian theories is difficult. The utilitarian view includes informing family members of the disorder and recommending testing. The rationale for this may increase if the disease is debilitating, untreatable, or fatal. If family members are not told of the possible harm, the principles of non-maleficence and justice are violated. The person is denied access to any possible medical treatment, social support, and financial support through governmental programmes. Even if medical treatment is not available at that time, it may be in the future as new technologies are developed every day. There may be a chance to be tested for a newly identified mutation, or enter an interventional research trial. If, however, family members cannot afford treatment, and programmes are not available, the decision to inform based on the burden/benefit ratio may change. On the one hand, the burden is increased without the opportunity to get help. On the other hand, informing them may protect future generations if they choose not to have children. Additionally, informing family members allows them time to make arrangements for their care and the care of their family. The health professional is in a unique and difficult position and must be protective of the population as a whole, yet not be derelict in the duty to respect personal privacy. A compromise should be made.

If the libertarian view was taken, it would come down to the choice of one person's right to make his/her own choices over several people's right to make their own choices. The libertarian theory allows a person to decide whether to be tested and whether to tell her family. She may fear discrimination or social isolation not only for herself, but also for family members. Choosing not to tell may protect a person's happiness and their chance to live a reasonably normal life. Choosing not to tell also upholds the family members' right not to know and to make choices free from influence.

Additional principles, such as non-maleficence, can be interpreted differently depending on whether the patient or the family member is the subject of interest. A person has the right not to know if he is at risk for a genetic disorder. Telling the person contravenes the principle of non-maleficence. Knowing about one's status may, however, actually decrease stress, thereby supporting the principle of non-maleficence.[2]

One must also be wary of the overemphasis on the utilitarian perspective within the area of public health. There is a legacy of eugenics throughout history. Eugenics was viewed as a scientific way to improve society and public health and became a social movement. Along with religious groups, the medical profession later became an opponent of eugenics and began demanding scientific proof of the benefit.[27] The eugenic movement in the US remains a prominent part of the history of public health.

The future will hold many new discoveries and changes of practice for genetic testing. The field is relatively new and always changing. Physicians, scientists, and public health professionals should always be prepared to accept new ideas, treatment options, and philosophies. Courses on ethics and genetics should be introduced into the curriculum for physicians and public health officials. The University of Michigan's Interdepartmental Concentration in Genetics in the School of Public Health has already introduced a class entitled Issues in public health genetics, and offers a model for other universities to follow.[1] Because more and more discoveries will be made in this field, physicians will need to be adequately trained in genetics and genetic counselling. Training should include continuing education after the physician is in practice. This education is important both because genetic testing is increasing, and the availability of genetic counsellors is limited and costly. This training would allow physicians to discuss issues with their patients in a manner that does not disrespect patient's rights. The patient may not know of risks to their families and the consequences of not telling them. Finally, if the physician is trained in genetic counselling, genetics, and ethics, he can help the patient to make a fully informed decision and to feel comfortable with properly defending that decision with regard to the rights of the patient herself and also to the rights of those affected by the patient's decision.

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