

Introduction

This session asks us to think about genetics and faith from a social justice perspective. We have already considered some ethical questions from the point of view of individuals and from the point of view of couples thinking of marriage. Parents are also faced with difficult situations when prenatal or pre-implantation genetic diagnosis indicates that their child, either at the embryonic or fetal stage, suffers from a serious illness or disability.

But what are the implications for policies that involve society as a whole? Health care is a good example.

Given the amount of money spent on health care in Canada, and the pressure to spend more, it is possible that emerging genetic technologies will not be covered by our health care system. Even now, new and expensive therapies are being carefully assessed for effectiveness and toxicity risks compared to the therapies they are meant to replace or supplement. Decisions for approving funding should be based on important outcomes such as improved survival or curability. Difficult decisions will be made that will likely exclude funding for some patients.

What type of genetic testing should be admissible and who should be considered eligible for such testing? Should it depend on whether a test is deemed life-saving (e.g., needed to determine urgent treatment)? What if it is requested for non-therapeutic reasons (e.g., the demands of insurance companies for a battery of tests)? Should these types of tests be publicly funded?

If expensive genetic technologies are publicly funded, making them more accessible, what health services would they displace? If genetic technologies are privately funded, how would we regulate the worst effects of the disparity in access? Will the ability to screen for more and more diseases and disabilities more and more cheaply lead to changes in our attitudes toward disability? Will there be increasing pressure not to produce any child with a disability? Will health



insurance, especially employer-based health insurance, pressure employees to take genetic tests to find pre-existing conditions? Will genetic knowledge change our ideal of equality as we discover great differences in our “natural endowments”?



We know from history what can happen when eugenics becomes acceptable policy. In the mid-twentieth century, Nazi Germany targeted people they considered not worthy of life and eliminated the mentally and physically disabled through sterilization and euthanasia.

Some people still believe that society should be cleansed of its mentally and physically “unproductive” members. This can come in the form of pressure to abort fetuses with physical or genetic evidence of mental or physical disabilities or threatening not to subsidize their care with public funds if they are allowed to live. Yet most of us become disabled in some way if we live into old age, no matter how strong and vigorous we have been in our youth. Will we, in turn, be perceived as “liabilities” and users of scarce resources? This is an

important question for a society in which the proportion of elderly citizens is steadily increasing.

The question of scarce resources concerns us all. With shrinking budgets and expanding medical and surgical possibilities, how do we decide what gets funding? Most of us believe our health care system operates on a fairly equitable basis, but some circumstances pose problems. For example, how do we decide who should receive donated organs when there are not enough to go around? Should younger people have priority? Is this discrimination against older people justified and if so, should other eligibility criteria be added?

Another social justice question is raised by pressure to introduce in Canada a fee-for-service system, or privatized health care, where a treatment may be prioritized on the basis of the ability to pay rather than need. The inability of poorer citizens with no extra insurance coverage to pay for drugs or dental care is also an ongoing social justice issue. No health care system is perfect and these issues are real and challenging.

Scenario 1

Question to Think About

*Will genetic technologies affect ethnically related social problems?
If so, how?*

There is a widespread belief that ethnicity is a genetic rather than a social characteristic, and, while it is true that certain ethnic groups are carriers of some specific diseases, it is not true that such diseases are confined only to those ethnicities. There is the danger that certain groups could be stereotyped or that, for example, intermarriages would be avoided out of fear of passing on genetic problems.

Francis Collins writes that "...race is an imperfect surrogate for ancestral geographic origin, which in turn is a surrogate for genetic variation across an individual's genome."

He notes that many think that race and ethnicity are too flawed as concepts to be helpful in working out race-health concerns. Although some diseases seem to be specific to some races or ethnicities, we have to be careful not to presume too much, nor to perpetuate stereotypes or prejudices linked to some diseases.

Narrative: The Use of BiDil

For the past two years you have been a member of a Health Canada committee that approves new drugs. You are currently charged with making a recommendation regarding the drug known as BiDil (isosorbide dinitrate and hydralazine hydrochloride). You are convinced that the drug is sufficiently safe and effective. You are concerned, however, about how the drug is to be marketed. Its maker, NitroMed, intends to market this drug to a particular ethnic population, based on studies that show it to be particularly effective in that group. Little was done to isolate the particular genetic profile that might make this drug more or less effective. You have done enough reading to understand the debate that approval of this drug will raise since it is being targeted for use in a particular group as though it were established that ethnicity is a genetic rather than a social category. Further, studies show there is more genetic variation within that group than in other ethnic communities. Overall, further studies show that BiDil has been effective in treating African-Americans, but it is feared that since only African-Americans participated in clinical trials, some think it is only effective within that group, whereas it may be more universally beneficial.

Discussion Questions

- 1) Even though you understand that there is a preponderance of evidence in favour of BiDil's safety and effectiveness, you also understand that the science behind the marketing decision is shaky. You know that the marketing will inevitably reinforce the dubious idea that ethnicity is a genetic category. You also understand that there will no doubt be a public controversy about the decision should the drug be approved for use in that particular community. How will you weigh these considerations?
- 2) Do you think your role on the committee should focus only on the safety and effectiveness of a drug or should you also consider social issues?

Scenario 2

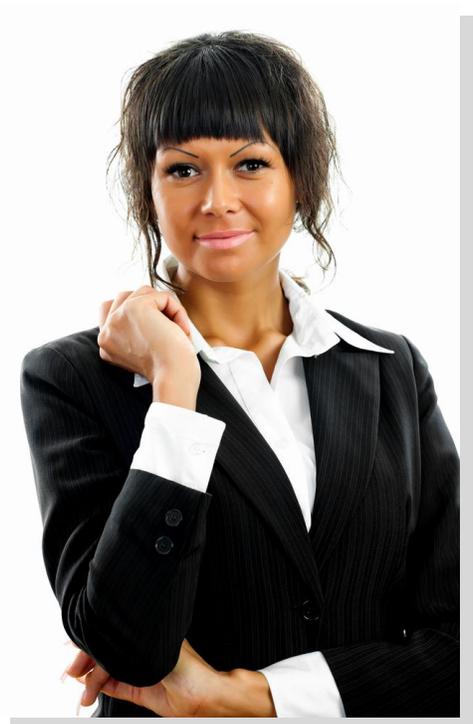
Question to Think About

What effect will genetic technologies have on the social and economic spheres?

According to Neil Postman, every technology has winners and losers, those who benefit and those who suffer. The film, "Gattaca," portrays a future society that is divided into two groups: the genetically engineered who are designed for the highest skilled jobs, and the "invalids" who are given menial tasks to support the work of the engineered class. Is the world of Gattaca a logical extension of the social and economic system we have today? Who will benefit from the genetic revolution? Who will suffer? What factors will shape how we use genetic technology?

Narrative: Genetic Testing and Employment Benefits

Janet is applying for a job at Maplekey, a large computer manufacturer. She is excited about this opportunity and looks over the job application very carefully. The company offers extraordinary benefits, particularly in the area of health. It pays 100% of all health related costs for employees and all immediate family members. There is just one caveat. The "health history" portion of the application includes genetic testing. All her immediate family members must be sequenced and profiled. The job is not dependent on the outcome of this test unless it reveals a life threatening or seriously debilitating disease which would affect Janet's job performance in the near future and cost the company a good deal of money. If the tests reveal the presence of a genetic marker linked to the high probability of less serious illnesses or disabilities Janet will still be offered a job, but her health premium and those of her family members will be based on the actuarial tables for the set of probabilities—the "risk pool" revealed in the genetic profiles. Janet seems to be in good health and she is not aware of any major health issues on either side of her family or that of her husband. Janet decides to discuss the situation with her husband, the kids, and you, her close friend.



Discussion Questions

- 1) This narrative is similar to the GenLife narrative in Session Two. Here, Janet and her family are being asked to disclose genetic information in exchange for a potentially good situation, a good job with great health coverage. As a close friend, what advice would you give to Janet?
- 2) It is a common, and some would argue reasonable, request that insurance applicants disclose pre-existing conditions. Physical exams and family health histories are sometimes part of the process of assessment and the assignment of a risk pool. How is genetic testing different, if at all, from this kind of risk assessment process?
- 3) What are the risks for Janet and her family when they take these tests? Apart from the possibility that Janet may be turned down by Maplekey, what other problems could arise?
- 4) Some argue that genetic technologies will either accelerate the demise of private insurance as a way of delivering health care or further isolate those with a less than ideal genetic inheritance. What do you think?
- 5) Does genetic testing have any place in assessing suitability for employment? Are there safeguards that could be put in place?

Scenario 3

Question to Think About

How will genetic technologies affect the allocation of health care resources?

Demands for testing for genetic information may affect health care budgets. For example, the daughters of women with breast cancer traceable to the BRCA1 and BRCA2 genes can be tested. Such testing has prompted many women to request pre-emptive mastectomy surgery based on probabilities of their developing breast cancer in the future. Even though not all the women would develop cancerous tumours, it's easy to understand the internal pressures that would lead to such requests. As more research uncovers genetic sources of disease, more of us will find ourselves anticipating outcomes and undergoing pre-emptive treatments where available. Since this will be statistically based, our health care resources will be further stretched, in some cases unnecessarily.

Narrative: Statistical Assessments of Successful Treatment

A 50-year-old man had surgery recently to have a malignant tumour removed from his colon. Certain features of the tumour suggest there is a high risk of the cancer recurring in the next five years. A treatment with some potentially troublesome side effects is



available that can reduce that risk by 20%. However, patients whose resected tumour possesses a certain mutation are much more likely to benefit from the treatment; that is, the tumour recurrence rate is reduced by 60% in patients whose tumour has the mutation while the rate is less than 5% in patients whose tumour does not have the mutation. A reliable test for this mutation is available but is very expensive due to patent protection.

Colon cancer is a relatively common cancer, so clearly, more lives can be saved by preventing cancer recurrence in patients whose tumours have the mutation. In addition, considerable health care funds are saved or deferred among treated patients whose tumours had the mutation. Therefore, the ministry of health decided to fund the genetic test that can discriminate which patients are more likely to benefit from the treatment.

Discussion Questions

- 1) What are the financial pros and cons of paying for tests for all patients who have a particular cancer that will indicate that the recurrence rate in some patients will be reduced by a certain treatment?
- 2) What would you do if a member of your family were told that she or he was ineligible for treatment?
- 3) Patent protection makes some treatments very expensive. Under our health care system, is non-funding of such treatments on the basis of expense (as opposed to efficacy) morally justified?