

Chapter 23

The Impact of Genetic Testing and Genetic Information on Ethical, Legal and Social Issues in North America: The Framework

Natalia Serenko
Lakehead University, Canada

ABSTRACT

This chapter discusses the impact of genetic testing and genetic information. It proposes a framework that facilitates a critical analysis of the ethical, legal, and social issues of genetic testing. The ethical effects include privacy infringement, genetic discrimination, misleading advertisement, psychological impact, and individual autonomy. The legal impacts embrace consistent terminology, referral guidelines, patent wars, and new legislations. The social effects pertain to inequality, higher insurance fees, tax burden, and fear of new eugenics. Information and communication technologies dramatically augment the effect of genetic testing on these outcomes. This chapter argues that information and communication technologies and rapid advances in genetics challenge the existing legislation systems in North America. Therefore, policy-makers need to address the tension between the potential benefits and harms of genetic testing and genetic information.

INTRODUCTION

This chapter presents and describes the framework of the impact of genetic testing and genetic information on ethical, legal and social issues in North America. In this framework, information

and communications technologies (ICTs) act as a catalyst that dramatically augments the effect of genetic testing on several critical outcomes. Implications for policy-makers and future research are discussed.

Rapid advances in genetics may be compared to an unprecedented revolution signifying a funda-

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mental shift in existing knowledge about medicine and health (Daar & Mattei, 1999). These scientific breakthroughs are due to information and communication technologies, which exponentially accelerate the growth of genetic knowledge. ICTs facilitate the accumulation of information obtained from genetic testing in very short periods of time (CBAC, 2004). ICTs allow organizations to keep people's personal data in the digitized form. As a result, the digital minds of computers store the enormous amounts of personal information that can be preserved for an indefinite period of time (Solove, 2001). The new information technologies transform industries creating needs, opportunities and threats. The health care sector is in need of using ICTs for various purposes. In fact, consumers expect the health professionals to utilize various information systems to improve the quality of service (Mercer, 2001). However, the employment of ICTs significantly increases the impact of genetic testing.

On the one hand, genetic testing may potentially generate many benefits for various stakeholder groups. On the other hand, genetic progress intensifies people's hopes and fears. Uncertainties about the genetic revolution are often discussed in the scientific literature, periodicals, and the Internet. Overall, these discussions suggest that losing control over genetic testing may do more harm than good (Rabino, 2003). Therefore, it is important to address the concerns associated with genetic technologies and genetic testing as soon as possible. The development of a control system over genetic testing may ensure that genetic testing is safe and benefits the entire society.

The form of genetic testing includes diagnostic, carrier, and predictive testing (Fulda & Lykens, 2006). Diagnostic testing is designed to identify the presence of genetic illnesses. The prenatal and newborn screening is the most common form of diagnostic testing. Carrier testing is performed to identify whether an individual inherited a specific genetic mutation. Predictive testing predicts

whether an individual with mutated gene will develop an illness.

Genetic testing can have both beneficial and harmful effects. It may help people identify, diagnose and prevent diseases. Other benefits of genetic testing include screening for rare diseases, chromosomal abnormality, Down syndrome, sickle cell anemia and phenylketonuria in newborns (Bassett, Lee, Green, Mitchell, & Kazanjian, 2004; Giacomini, Miller, & Browman, 2003). However, genetic testing advancements also lead to a number of critical ethical, legal and social issues which are described below in detail.

THE ETHICAL, LEGAL AND SOCIAL ISSUES FRAMEWORK

Overview

The proposed ethical, legal and social issues framework explicates the major types of genetic testing impact. The ethical effects include privacy infringement, genetic discrimination, misleading advertisement, psychological impact, and individual autonomy. The legal impacts embrace consistent terminology, referral guidelines, patent wars, and new legislations. The social effects pertain to inequality, higher insurance fees, tax burden, and fear of new eugenics. Information and communication technologies dramatically amplify the effect of genetic testing on these outcomes. Figure 1 presents the framework.

There are several reasons why genetic information has special status. Genetic tests produce very comprehensive information about an individual's health risks. This genetic information can be easily tracked back to his or her family members. A genetic family 'blueprint' cannot be changed. Genetic samples can be kept almost indefinitely in DNA banks, laboratories, hospitals, research centers and pharmaceutical companies. Some of these storage services are free and some are fee-based (CBAC, 2004).

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