Chapter XXXI

Predictive Genetic Testing, Uncertainty, and Informed Consent

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ABSTRACT

This chapter focuses on showing legitimate ways for coping with uncertainties within the informed consent process of predictive genetic testing. It begins by indicating how uncertainty should be theoretically understood. Then, it describes three dimensions of uncertainty with regard to both the role of genes in pathogenesis and the benefit to patients of undergoing predictive genetic testing. Subsequently, the ways by which institutions tame these uncertainties are explained. Since viewing genes as exceptional informational entities plays an important role in taming uncertainties, it explains why this conception should be abandoned. Then, it discusses how institutional taming of uncertainty becomes a source of paternalism. What is stressed is that in order to avoid paternalism and ensure transparency within the informed consent process, open-to-uncertainty mechanisms should be implemented before the public and the individual. How patients should deal with potential implications of testing for their relatives is also considered.

INTRODUCTION

As is well known, predictive genetic testing has been considered an important tool for the prediction of the future health status of an individual. As such, this includes presymptomatic and predisposition tests, which determine the risk of developing a particular disorder by identifying a single or several genes presumably related to it, as well as pharmacogenetic tests, which determine the predisposition of individuals to react differentially to drugs (European Commission, 2004). Since it is expected that our knowledge about the role of combined genes in pathogenesis and drug reaction will grow in the immediate future, clinical institutions and physicians have confidence in the increasing role of this technology within the health care setting. A lot of declarations and writings have been provided concerning this promising future, and several specialized institutions already have arisen to activate this new technology (genetic centers). In the same way, lay people have introduced "genetic language" to explain their potential diseases as well as to redefine what they understand by "medical care."

This chapter analyzes the process of activation of this new technology from an institutional-constructivist point of view, considering the consequences for understanding and implementing the informed consent process. In this sense, this chapter attempts to remain in the happy middle ground between social analysis of science, which conceives of ethical and political problems as issues that should be analyzed only in a descriptive way, and ethical and political approaches to science and technology that leave aside the problem of the institutional complexities which indeed may impede an appropriate fulfillment of normative demands.

What the chapter pursues is a clarification of how, in the field of clinical genetics, the institutions frame uncertainties in a way that allows them to reduce those uncertainties and manage them. Because there are strong reasons to consider this framing judgment as a way of bypassing the autonomous deliberative process, this chapter stresses that in order to avoid this undesirable effect and ensure transparency, it is necessary to focus on procedures that "coping with untamable uncertainties and complexities" (Van der Slijs, 2006, 68) before the public and the individual.

Bypassing paternalism undermines due respect for autonomy, since it implies that a person will not decide on the basis of unbiased prospects of action. On the contrary, because of being confronted with biased information, he/she will decide in a predictably induced manner. It is broadly accepted that the rhetorical framing of information undermines the free formation of the person's will. Certain ways of communication can *induce* a person to adopt causal beliefs that clearly favor the values or interests of the person or institution that communicates. As Stokes (1998) has correctly pointed out, these ways of communication should be considered as pathologies of deliberation as long as they induce certain preferences in the people by providing them with value-laden information. In order to prevent this undesirable situation, it is mandatory that people deal with a deliberatively processed picture of prospects. As I will show, only through this method can people deal with an impartial view of the situation at stake. The implementation of *postnormal* ways of mapping, assessing and disclosing scientific information is therefore mandatory.

DEFINING UNCERTAINTY

Although uncertainty has been systematically understood as a situation in which knowledge about a topic can be described as inexact, unreliable or almost absent (Funtowickz and Ravetz, 1990), it is more useful, as Walker et al. have pointed out, to understand uncertainty as a *multi-dimensional concept* that in general terms refers to the "deviation from the unachievable ideal of completely deterministic knowledge of the relevant system" (Walker et al., 2003, 5). Therefore uncertainty represents a cognitive situation not necessarily related to a lack of knowledge (2003). In fact, an increase of knowledge "can either decrease or increase uncertainty" (Walker et al., 2003, 8).

Instead of conceiving of uncertainty as a cognitive situation that only emerges when, given a particular set of inputs, there is incomplete knowledge about *future scenarios*, as Hansson (1996) and Vlek (1987) had raised in their classical contributions, Walker et al. have helped to widen the spectrum of what uncertainty implies. From their point of view, unavoidable theoretical uncertainties about the basic presumptions that

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