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Susceptible Individuals and Risky Rights: Dimensions of Genetic Responsibility

(Abstract)

Repeatedly it has been remarked that the results of genomic research are threatening traditional concepts of personal responsibility and individual autonomy.¹ Contemporary biology with its search for genetic (and neurobiological) determinants for a multitude of traits and modes of behavior seems to subvert the substantial basis for responsible action: the possibility of individual decision-making and choice. I do not think that this fear of genetic determinism is justified. What we observe today is not the reduction of individual responsibility by reference to genetic dispositions and inborn traits. The discovery of genetic factors that influence and regulate the expression of diseases and personal traits does not result in a position that negates or forecloses the responsibility of the subject; quite on the contrary, the increasing genetic knowledge is the central point of reference to expand moral duties. It engenders new modes and fields for responsible action.

In this paper I would like to highlight a few dilemmas and problems presented by the discourse of genetic responsibility. Since the focus in the research literature as well as the coverage in the media has been on “responsible parenthood”, I will concentrate in this contribution on the two other dimensions of genetic responsibility. My thesis is that the discourse of genetic responsibility tends to undermine guaranteed rights and the freedom of choice concerning genetic tests by establishing imperatives of duty towards oneself and others. Firstly, the duty to inform relatives about their genetic risks may contrast with the protection of privacy and the confidentiality of the doctor-patient relationship. Moreover, the imperative to warn others could erode their right not to know about genetic risks. Secondly, new forms of discrimination, exclusion and paternalism might arise in a social and political

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conjuncture in which genetic information is becoming more and more irresistible. In this social climate it will probably be judged responsible to exclude workers diagnosed as genetically susceptible from health threatening job positions.

In the following sections I'll concentrate on how the responsibility to communicate and control genetic risks already shapes juridical decisions and how it takes hold in institutional settings such as the patient-physician relationship and in the workplace. I will present several legal cases that were recently decided in the US, which serve to illustrate the dangerous trend in which the duty to inform relatives as well as the imperative to control one's own genetic risks are becoming institutionalized.