

Ethical Discussions on Prenatal Diagnosis: Iranian Case of Thalassemia Prevention Program

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Abstract : Objectives: The purpose of this paper is to investigate the social policy of preventive genetic medicine in Iran, by following the legalization process of abortion law and the factors affecting the process in wider Iranian contexts. In this paper, ethical discussions of prenatal diagnosis and selective abortion in Iran will be presented, by exploring Iranian social policy to control genetic diseases, especially a genetic hemoglobin disorder called Thalassemia. The ethical dilemmas in application of genetic medicine into social policy will be focused. Method: In order to examine the role of the policy for prevention of genetic diseases and selective abortion in Iran, various resources have been studied, not only academic articles, but also discussion in the Parliament and documents related to a court case, as well as ethnographic data on living situation of Thalassemia patients. Results: Firstly, the discussion on prenatal diagnosis and selective abortion is overviewed from the viewpoints of ethics, disability rights activists, and public policy for lower-resources countries. As a result, it should be noted that the point more important in the discussion on prenatal diagnosis and selective abortion in Iran is the allocation of medical resources. Secondly, the process of implementation of national thalassemia screening program and legalization of 'Therapeutic Abortion Law' is analyzed, through scrutinizing documents such as the Majlis record, government documents and related laws and regulations. Although some western academics accuse that Iranian policy of selective abortion seems to be akin to eugenic public policy, Iranian government carefully avoid to distortions of the policy as 'eugenic'. Thirdly, as a comparative example, discussions on an Iranian court case of patient's 'right not to be born' will be introduced. Along with that, restrictive living environments of people with Thalassemia patients and the carriers are depicted, to understand some disabling social factors for people with genetic diseases in the local contexts of Iran.

Keywords : abortion, Iran, prenatal diagnosis, public health ethics, Thalassemia prevention program

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