Genetic testing incorporated into clinical care: Ethical considerations

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Genetic testing has been increasingly used in the clinical setting in the last twenty years. Certain genes have been strongly associated with the development of certain illnesses or cancers (the BRCA gene confers 50 to 80% lifetime risk of developing breast or ovarian cancer). The test is used primarily in screening individuals at high risk in families with early onset breast or ovarian cancer. BRCA is not the only gene associated with cancer, and others like APC (predisposing to colorectal cancer) and RET (associated with MEN 2 syndrome) have been discovered and are increasingly tested for in clinical settings. In addition, many other genes involved in non-cancerous illnesses have also already been identified and studied. Associated with those medical advances, new ethical implications emerge that need serious consideration and perhaps a shift in mindset of both the general population and the scientific community.

As an emerging practice, genetic testing should be analyzed in terms of its ethical implications and certain definitions must arise from the questions it prompts. These include the nature of the genetic information that should be generated, the procedures that are to be allowed, the definition of genetic normalcy, as well as the impact these tests might have on the lives of the individuals concerned, the community and society in general. Failure to do so might have serious consequences due to the potential for abuse and the risk of falling into unethical practices. In order to achieve analysis and consequent ethical practice, one needs to realize the fundamental difference between traditional laboratory testing that is commonly used up until now and the new promising genetic testing. This difference arises from the inherent nature of genetic knowledge, which is more individual, predictive and probabilistic (Surborne, 151). Hence, whereas a traditional lab test will give you information about the current state of a disease process in an individual, BRCA testing will tell you about the lifetime risk that an individual carries of developing breast or ovarian cancer at some point in her life. The most fundamental principles of medical ethics risk being shaken by the shift of genetic testing from the research arena to the clinical arena. In protection of autonomy for instance, informed consent has been an absolute prerequisite, and it should include the technical and medical aspects of the test, as well as discussion of its social and ethical implications. Also, individuals should be provided with the right “not to know”. The principle of beneficence must also be considered as genetic testing should only be carried out in the setting where measures can be taken in prevention of the cancer or early diagnosis can be achieved. In terms of non-maleficence, the psychological burden of knowledge about one’s future cancer risk is still evasive and serious research still needs to be carried out to evaluate it. As far as justice is concerned, some very important issues arise with genetic testing. Care must be taken to establish a proper framework for the information obtained through genetic testing in terms of confidentiality as well as in terms of ownership and access to the information, as it carries a significant risk of predisposing individuals to discrimination in issues concerning life or health insurance, employment, as well as in the microenvironment, the process of adoption, and prenatal diagnosis.

Although genetic testing is still in a rather early stage of development, it has great potential, and its impact on the individual, community and social levels could be pharaonic. The power and responsibility it implicates are considerable. Consequently, equal progress must be made in
defining all the unanswered questions genetic testing generates, so as to protect the pillar principles upon which biomedical ethics stand and allow for a flourishing evolution of this new biomedical technology within a virtuous framework.

References: