PIII-16: Informed decision making in prenatal genetic testing: A review of the literature

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Abstract:
Introduction: Informed decision making is having adequate knowledge when making decisions about some aspect of one’s health. Autonomy is the ethical principle of allowing an individual to state their opinions and making decisions. In health care, having autonomy is very important however, to make these decisions, having the adequate knowledge to ensure the decision is informed and ethically sound. The purpose of this literature review is to systematically review the current literature on informed decision making in prenatal genetic testing. The research question is: What are the characteristics of informed decision making in prenatal genetic testing?

Method(s): A systematic review of the literature was conducted by searching Medline and Cinhal databases using the terms “informed decision making”, “autonomy”, “prenatal”, “genetic” and “genet*” resulting in 330 unique research articles. Sample inclusion criteria were applied: a) published within the past ten years, b) written in English, c) qualitative and/or quantitative methods, and d) included women or both women and men. Based on the sample criteria, the 330 articles were reduced to 21 articles for review.

Results: Preliminary findings show that about 51% of individuals make a truly informed choice when deciding whether to allow prenatal genetic testing. This is made clear by the significant differences that exist between those that state they intend to have testing done and actual testing behaviors. The literature shows individuals felt there was a lack of information, poor quality information and feeling negatively targeted based on race when getting prenatal genetic testing. The ethical implications of these preliminary findings are limitless. In no way is the ethical issue of autonomy being upheld in this setting.
Discussion & Conclusions: Unfortunately, at this time, no universally accepted guidelines exist for communicating genetic-risk information and too many prenatal genetic testing decisions are made without adequate information. In order to adequately preserve the ethical principle of autonomy, it is the duty of all medical care providers and professionals to ensure, that when providing care to individuals, all decisions made about prenatal genetic testing are done with an adequate information and knowledge.

Abstract History:
This abstract has not been presented or accepted for presentation in whole or in part at the SNRS or other scientific meeting.

Financial Disclosure:
No, I (or a member of my immediate family) have not received something of value* from or own stock (or stock options) in a commercial company or institution related directly or indirectly to the subject of my presentation.

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I will not be describing any pharmaceutical and/or medical device.

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