Why do people undergo genetic testing – for personal benefits, for family, or for science and society?

Genetic testing is an important tool to detect gene mutations (e.g., *BRCA1/2*) that increase the risk of cancer, especially among those who are known to have higher chances of carrying these mutations such as Ashkenazi Jewish individuals. Genetic testing helps in estimating the chances of developing cancer among such individuals as well as his children and family so that they can take preventive steps in the future. Thus, it is important to understand people's reasons to undergo genetic testing – whether for themselves or for family or to advance research and if these reasons change after genetic counseling and testing.

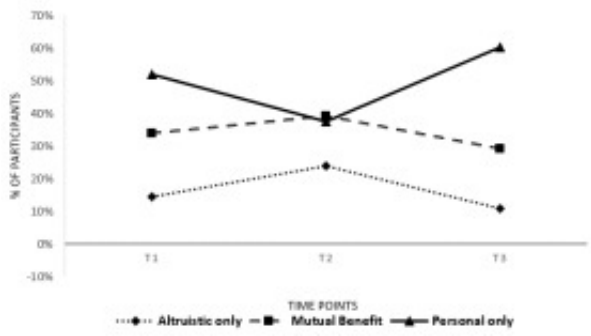

Fig. 1. Change in motivations to test over the 6 month study period (N=120). T1: Before genetic counseling, T2: 1-2 days after genetic counseling and T3: 6 months after the receipt of genetic test results.

In this study, we evaluated Ashkenazi Jewish individuals' reasons to pursue genetic testing and the change in these reasons after genetic counseling and testing. The 120 participants were recruited as part of a larger study, which offered free genetic counseling and genetic testing. We surveyed the participants at three time points: before genetic counseling (T1), after genetic counseling (T2), and after genetic testing (T3). Further, we analyzed the transcripts of genetic counseling sessions to understand the context of people's decision to undergo testing.

From our study results we found that before genetic counseling, individuals cited following top reasons to undergo genetic testing: for personal cancer prevention (64.3%), to acquire knowledge of their genetic status and their risk of cancer (42.0%), for benefit of family (25.0%), to lower their anxiety (16.1%), to advance science and research (13.4%), and for future planning such as having kids earlier or finding a suitable partner (5.4%). Thus, we found that the top most reason to undergo genetic testing was for personal benefits. A lot of individuals, however test for their family and for society as well. Next, we evaluated the factors that influence an individual's reason to undergo testing. Interestingly, we found that those who had been diagnosed with cancer before

and those who had one or more children were significantly more likely to report testing for their family and society. During genetic counseling session, one woman specifically noted that her own personal experience of coping with cancer led her to be concerned for her children and other family members. Further, it is recommended that the individual who had cancer previously should test first to identify the gene mutation and provide information to other family members. These might be the reasons why those with history of cancer wanted to test for their family and to advance research.

Another significant result of our study was that individuals' personal reasons to test significantly decreased while their reasons to test for family and society significantly increased after genetic counseling. During genetic counseling, family history, mechanism of cancer inheritance, and chances of passing gene mutations to children are discussed. This discussion might have led to a better understanding of implications of genetic testing for family's risk of cancer and the survival of future generations. After genetic testing, the personal reasons increased and reasons to help family decreased to their original values.

Our study results have important implications for genetic counselors and individuals with a family history of cancer. Although these reasons to undergo testing were previously considered static, our study proves that they are open to change through genetic counseling. The study further provides important insights into the opportunity to discuss the implications of genetic testing for family members, an important role of genetic counselors. Future studies should explore the risk communication process and motivations to give and receive genetic information in the context of family. Further, genetic counselors may want to more routinely discuss other benefits of genetic testing such as the potential to improve science through the participation in research.

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Publication

Impact of Genetic Counseling and Testing on Altruistic Motivations to Test for BRCA1/2: a Longitudinal Study.
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