Non-genetic health professionals’ perceptions of genetic testing for hereditary cancer

Over the last decade more genetic tests are being ordered by non-genetic health professionals, such as oncologists, gynecologists, and primary care providers. Numerous studies have shown that non-genetic health professionals have insufficient knowledge of genetics, express educational needs and are generally unprepared to counsel their patients regarding genetic test results. Inadequate genetic counselling and testing can lead to negative outcomes in patients and their families. However, so far, not much is known about what non-genetic health professionals who order genetic testing themselves think about their communication skills.

Two publically accessible databases, The Myriad Genetics Find a Healthcare Provider website (www.myriadtests.com/finddoc.php) and the National Cancer Institute (NCI) Cancer Genetics Services Directory (www.cancer/gov/cancertopics/genetics/directory) were used to invite non-genetic health professionals providing cancer genetic services to complete a questionnaire. In total, 45 non-genetic health professionals participated.

In contrast to known studies showing that providers are unprepared to counsel their patients, our study shows that most non-genetic health professionals ordering cancer gene testing have a positive attitude towards, knowledge of and skills in discussing and ordering genetic testing for cancer. They feel responsible for enabling disease and treatment related behaviour, such as preventive screening. However, our study may have suffered from response bias, as our respondents may be those who view this as an important process whereas those who do not may not have responded. This may have led to an overrepresentation of experienced and well-trained non-genetic health professionals.

Most of the respondents have a positive view of their own information giving and decision making skills. However, 20-30% reported difficulties managing patients’ emotions and did not see management of long-term emotions as their responsibility. The majority of our respondents however are involved in long-term management of at-risk patients and should be prepared to address these emotions.

Correct answers on knowledge questions ranged between 41-96%. Only three persons gave the correct answer to all knowledge questions. Investigation of individual items shows that respondents know least about consequences for other family members. This might lead to family members being less well informed if people get tested through a non-genetic health professionals. This definitely warrants further investigation. Also, the fact that more than 30% of participants are unsure how to interpret a variance of unknown significance (VUS) is a reason for concern, as the number of VUS will increase with the current application of next generation sequencing (NGS) in the United States.

Our study showed that the higher the knowledge level, the more confidence non-genetic health professionals reported in information giving skills. This association suggests that awareness of knowledge gaps affects health professionals’ confidence. This suggests that knowing your limitations makes non-genetic health professionals more willing to get further education. In addition, this could also mean that they value more the contribution that genetic professionals make to the emotional aspects that arise during counseling session and the genetic professional expertise.

To conclude, our study raises several concerns about how well-informed patients and their families will be. Specific attention is needed for the consequences of genetic testing for family members and the interpretation of VUS. Continuing medical education should address these issues.

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