Impact of Direct-to-Consumer Genetic Testing

To the Editor: I would like to thank Gray and Abel for their thoughtful article in the March issue of *Journal of Oncology Practice* on the direct-to-consumer marketing (DTCM) movement in oncology.¹ Clinicians should not underestimate the impact and potentially negative ramifications of this practice in the realm of genetic testing for hereditary predisposition for a diagnosis of cancer. The authors correctly note that few published studies have directly addressed the impact of DTCM on behavior and, more important, psychosocial well-being.

The practice of DTCM is complicated in genetic testing. Marketing targets both the public and health care providers, including primary care providers, who may have limited knowledge of genetics and oncology.² When genetic testing occurs outside of the setting in which there is access to genetics professionals, including physicians board certified in genetics, masters degree-level genetics counselors, and advanced practice nurses with a genetics credentials, the risk of negative outcomes is greatly increased.³ Several professional organizations have issued position statements that warn about the risks of DTCM. These include the Oncology Nursing Society,⁴ National Society of Genetic Counselors,⁵ American Society of Human Genetics,⁶ American College of Clinical Pharmacology,⁷ American Congress of Obstetricians and Gynecologists,⁸ American College of Medical Genetics,⁹ European Society of Human Genetics,¹⁰ and ASCO.¹¹ In general, all of these position statements express concerns that patients may not understand the impact of genetic testing results, be unprepared for the test results, be uninformed of the recommended screening or follow-up based on the results, or experience psychosocial distress when genetic testing occurs without informed pre- and post-test genetic counseling.

The psychosocial impact of poorly informed genetics testing is very real. In the past year, I have personally observed three women self-refer for genetic education and counseling services after learning they are at risk for one of the three founder *BRCA* mutations commonly seen in persons of Ashkenazi Jewish background, on the basis of an online DTCM test. In each case, the at-risk finding was confirmed in another laboratory. All three women had done the test out of curiosity. One had received it as a 50th birthday gift

from a well-meaning friend, one had done it with her husband as an anniversary present to each other, and one had done it with her fiancé strictly out of curiosity. None had genetic counseling, although it was available at the Web site for an additional charge. None was prepared for the possibility that they had a possible 90% lifetime risk of developing breast cancer and a 40% lifetime risk of developing ovarian cancer.¹² Each was devastated by the diagnosis, and this response was compounded by the psychosocial distress of being unprepared for the results and the associated prevention and surveillance recommendations including prophylactic surgery. Each woman has required many hours of psychosocial support that may have been avoided with proper pretest counseling. All have begun to make difficult decisions about prophylactic surgery. DTCM does not appear to provide this type of counseling and support. More important, it does not identify other family members potentially at risk and provide them with psychosocial support, education, and coordinated genetic testing. In each of these women's families, there were other members at risk. A genetics professional knows to identify other at-risk members and assists them with counseling or to coordinate it in another geographic area as indicated. DTCM for genetic testing appears to have much more than entertainment value, and those who respond to DTCM for genetics testing may be at significant risk for not understanding the implications of a test and the importance of engaging in adequate prevention and early detection maneuvers. They may also experience psychosocial distress as a result of being unprepared for the test results, and may not receive information on coordinated care for other at-risk relatives. Clearly, more research needs to be done to verify clinical findings resulting from DTCM tests. Clinicians should realize that the risks from DTCM for genetic testing are real and potentially devastating.

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