Challenges Associated With Hereditary Cancer Susceptibility Testing

I would like to thank Linda Wasserman, RN, MN, BC, for having the insight to submit her story about the testing experience for the BRCA1 and BRCA2 mutations (Wasserman, 2013). As a genetics professional, I am always awed and humbled by the courage displayed by these women and their families as they navigate all of the challenges that accompany hereditary cancer susceptibility genetic testing.

Like most of the families I care for, in time, adjustment occurs and they are at peace with the decisions they have made and how they have used the knowledge gained by genetic testing to have a positive outcome. As the author so correctly noted, adjustment is clearly enhanced by having a strong support system (Rew, Kaur, McMillan, Mackert, & Bonevac, 2010).

Wasserman’s story also is not unfamiliar to me with regard to the challenges and disappointments that occur when genetic testing is not accompanied by comprehensive counseling by a credentialed genetics professional. She noted that it is a simple blood test (or more often a mouthwash buccal cell collection), but nothing is simple about it. Collecting the test specimen and even figuring out how to pay for the test is not the challenging facet of genetic testing. Ensuring that the patient has adequate information prior to testing is critical. Unfortunately, Wasserman’s test was ordered quickly and without the benefit of counseling. Wasserman and her family members did not appear to receive detailed and supportive discussion of the consequences and implications of testing. Without risk assessment and counseling, a very real risk exists that the wrong test will be ordered; however, that was not the case for Wasserman (Brierley et al., 2012). One of the biggest consequences of ordering genetic testing without the support of a genetics professional is that care will not be coordinated for the rest of the family. When a genetic mutation is detected in a family, psychosocial and risk implications exist for the entire family, not just the person tested. Providing comprehensive care for the entire family is critical to prevent cancers in other members who have inherited risk and to have the best possible psychosocial and cancer-free outcome (Brierley et al., 2010; Mahon, 2009).

A multitude of ways exists for oncology nurses to support individuals and families. It starts with the identification of people at risk and a referral to the genetics professional. For Wasserman, despite her dramatic family history, a number of professionals, including a nurse practitioner, failed to recognize her risk factors for hereditary breast and ovarian cancer and to take the steps to ensure comprehensive genetic counseling and appropriate testing. Oncology nurses also need to ensure that individuals and families who have a mutation receive continual support and education throughout the testing process and, for those who test positive, during and after prophylactic surgical procedures (Matloff, Barnett, & Bober, 2009). However, the psychosocial needs of those who test negative and their partners should not be underestimated (Sherman, Kasparian, & Mireskandari, 2010).

The recent revelation by Angelina Jolie that she has a mutation and had undergone prophylactic surgery, and the release of the movie “Decoding Annie Parker” have heightened public awareness of the challenges these families face (Kluger & Park, 2013). Thank you to Linda Wasserman for articulately sharing her story as well.

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References

Selection of letters to be published is the decision of the editor. For acceptance, letters must be signed. A letter can appear anonymously if requested by the author. All letters are subject to editing. A letter that questions, criticizes, or responds to a previously published Clinical Journal of Oncology Nursing article automatically will be sent to the author of that article for a reply. This type of collegial exchange is encouraged. Send letters to CJONEditor@ons.org.

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but the authors do not suggest offering those individuals treatment for tobacco dependence that could reduce their risk for developing many cancers and other comorbid conditions. In fact, the American Cancer Society (2013) noted that the recommendations for screening for lung cancer do not serve as a replacement for quitting smoking. The most important thing a heavy smoker can do to reduce their risk of lung cancer is to quit smoking or using any form of tobacco. No mention was made of this critical intervention anywhere in the article that aimed to guide nurse navigator clinical practice.

The National Comprehensive Cancer Network’s (2013) guidelines for lung cancer screening also recommend that all current smokers be advised to quit and that former smokers be supported to stay abstinent. The guidelines also provide resources and include a statement that screening should not be a substitute for smoking cessation.

I hope that CJON will consider sending information about how nurses can help smokers quit to every nurse who reads this article and completes the test for continuing education credit. Some information can be found at www.ahrq.gov/legacy/clinic/tobacco/clinhlpsmksqt.htm.

References


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The Author Responds
I certainly acknowledge the importance of smoking cessation as the primary factor in the prevention of lung cancer, and I also certainly appreciate the contributions that Dr. Sarna has made in her efforts to educate and promote smoking cessation programs among nurses and to the general public. However, the purpose of that article was to describe the management of lung nodules for nurses and, as such, the subject matter was quite narrow.

As a lung cancer navigator, the goal established in our program was to improve timeliness in the diagnosis of lung cancer from first abnormal screening test to resolution, and a key part of this was to identify barriers to care including patient, provider, and institutional barriers. One identified area where patients fell through the “healthcare cracks” was found to be in the follow-up and management of suspicious lung nodules.

As a diagnostic navigator, it was essential that I understood the biology and histology of lung nodules suspicious for cancers. Given the increasing institutional emphasis and support for cancer navigation, the intent of the article was to share with others my knowledge of the management of suspicious lung nodules that can lead to earlier diagnosis and treatment of lung cancer.

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Correction
In the December 2013 issue of the Clinical Journal of Oncology Nursing (CJON), “Monoclonal Gammopathy of Undetermined Significance—Making It Understandable to Patients” by P. Rule and J.M. Brant (Vol. 17, No. 6, pp. 614–619) did not include its disclosures. The authors were participants in the CJON Writing Mentorship Program, and Brant received honorarium from the Oncology Nursing Society for her role as a mentor.