Gynecologic Oncology Reports 14 (2015) 44–45

Contents lists available at ScienceDirect

Gynecologic Oncology Reports

journal homepage: www.elsevier.com/locate/gore

Correspondence

Genetic counseling and testing for hereditary cancer risk in young adult women: Facilitating autonomy and informed decision making is key

We read with interest the Society of Gynecologic Oncology's (SGO) statement on risk assessment for inherited gynecologic cancer predispositions (Lancaster et al., 2015). We commend the authors for their comprehensive and thoughtful review of genetic counseling and testing issues. However, we respectfully disagree with the SGO's position to "not recommend genetic testing of women under age 21 for HBOC [Hereditary Breast & Ovarian Cancer] or Lynch [syndrome] in the absence of a family history of extremely early-onset cancer." To be clear, we are not advocating for routine testing in minor children, but are concerned about the recommendation specifically as it applies to 18 to 20 year-old women.

The authors correctly state that because the cancer risks in HBOC syndrome (due to *BRCA1* and *BRCA2* [*BRCA*] mutations) and Lynch syndrome are very low in women under age 21, management recommendations are generally unchanged. The authors also state their concern about the "potential negative consequences of genetic testing" (Lancaster et al., 2015). Based on these two reasons, the SGO made the recommendation that, with rare exceptions based on family history presentation, young adult women should not be tested for these cancer susceptibility gene mutations.

We believe that discussing and potentially offering genetic testing to high risk women age 18 and older is appropriate in the context of pre-test genetic counseling and informed consent regardless of the ages of cancer diagnoses in their family. For simplicity, we frame our position as it applies to the example of 18 to 20 year-old unaffected women who have a biological relative with an identified *BRCA* mutation. If a mutation is present in a first-degree relative, then these young women have a 50% risk of testing positive. In addition, we assume that no relatives have been affected with an "extremely early-onset cancer" (e.g., breast or ovarian cancer diagnosed before age 30). We believe that the general arguments discussed below apply also to those at-risk for Lynch syndrome and other hereditary cancer predisposition syndromes.

There are several strong arguments for offering genetic counseling and possible testing to interested 18 to 20 year-olds at high risk for carrying a *BRCA* mutation. For example, there are potential medical implications to them even though national guidelines do not recommend screening with annual clinical breast exams and breast MRI exams until age 25 (National Comprehensive Cancer Network Inc., 2015) and risk reducing mastectomy is rarely, if ever, performed in 18 to 20 year-olds. However, young women may still wish to make informed decisions about other medical issues such as oral contraceptive use (Hoskins et al., 2014). Oral contraceptives decrease ovarian cancer risk in *BRCA* carriers, and do not appear to increase their breast cancer risk (Moorman et al., 2013). Thus, not only is oral contraceptive use not contraindicated in *BRCA* carriers, but it may be encouraged by some clinicians as a strategy to reduce ovarian cancer risk (Narod, 2004). Some young women may not be knowledgeable about this information and may pursue testing to make a decision about use of hormonal birth control.

Because 18 to 20 year-olds are of reproductive age, it is also important that they be made aware of reproductive options such as pre-implantation genetic diagnosis (National Comprehensive Cancer Network Inc., 2015). Although childbearing may not be imminent for women in this age group, they should still be informed about reproductive options because relationship formation and life planning may be prominent tasks of this life stage (Werner-Lin et al., 2012).

However, we assert that the most compelling argument against a policy of not testing 18 to 20 year-old women is that, with proper genetic counseling, these individuals may derive significant psychological relief from testing. A critical part of the genetic counseling process is to assess psychological concerns and to provide individualized resources and support (Riley et al., 2012). Research has demonstrated that women who test negative for a familial *BRCA* mutation experience a significant reduction in distress compared to pre-test levels (Beran et al., 2008; Schwartz et al., 2002). Moreover, distress among women who test positive does not appear to reach clinically significant levels or to persist by the one-year mark after testing (Beran et al., 2008; Schwartz et al., 2002). Although women who test negative for a familial mutation are likely to experience the most significant psychological benefits from testing, the relief from uncertainty may be empowering even to those who test positive.

We acknowledge that little research has been done characterizing young at-risk women specifically and their psychological outcomes following genetic testing. Concerns have been raised about how these young women may cope with genetic testing results (Werner-Lin et al., 2012). However, there is no evidence that they are likely to suffer adverse consequences from genetic testing when it is pursued in the setting of comprehensive genetic counseling. Because young adult women are increasingly seeking out genetic testing for hereditary cancer risk, continued research to assess best practices and outcomes is important.

A cornerstone of genetic counseling is to facilitate and foster patient autonomy. After genetic counseling, some young women may choose to pursue genetic testing, and others may defer it until they feel more prepared to assimilate the results, both psychologically and/or medically. Genetic counseling is designed to provide information and support regardless of a woman's testing decision. Genetic counseling is also an opportune time to correct misinformation about risk and risk management, and for young women to discuss concerns about their worries, plans, family formation, and existing family dynamics (Hoskins et al., 2014; Hoskins and Werner-Lin, 2013). We believe that a blanket recommendation against offering genetic testing to young adult women compromises their autonomy and may deter them from pursuing genetic counseling.

DOI of original article: http://dx.doi.org/10.1016/j.ygyno.2014.09.009.

http://dx.doi.org/10.1016/j.gore.2015.10.001

In sum, we support a recommendation that adults who are at increased risk for hereditary cancer syndromes, including 18 to 20 year-olds, should be offered genetic counseling. This process enables patients to make informed decisions about genetic testing and management based on the associated potential benefits, limitations, and risks, as well as their own values, preferences, and goals. Therefore, we encourage members of the SGO Clinical Practice Committee to reconsider their recommendations in this regard.

Conflict of interest statement

No potential conflicts of interest were disclosed.

References

Lancaster, J.M., Powell, C.B., Chen, L.M., Richardson, D.L., 2015. Society of Gynecologic Oncology statement on risk assessment for inherited gynecologic cancer predispositions. Gynecol. Oncol. 136 (1), 3–7.

National Comprehensive Cancer Network Inc., 2015. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Genetic/Familial High-Risk Assessment: Breast and Ovarian. Version 2.2015. (www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf (Accessed July 8, 2015)).

Hoskins, L.M., Werner-Lin, A., Greene, M.H., 2014. In their own words: treating very young BRCA1/2 mutation-positive women with care and caution. PLoS One 9 (2), e87696.

Moorman, P.G., Havrilesky, L.J., Gierisch, J.M., Coeytaux, R.R., Lowery, W.J., Peragallo, U.R., et al., 2013. Oral contraceptives and risk of ovarian cancer and breast cancer among high-risk women: a systematic review and meta-analysis. J. Clin. Oncol. 31 (33), 4188–4198.

Narod, S., 2004. The prevention of hereditary breast and ovarian cancer: a personal view. Hered. Cancer Clin. Pract. 2 (1), 5–10.

Werner-Lin, A., Hoskins, L.M., Doyle, M.H., Greene, M.H., 2012. 'Cancer doesn't have an age': genetic testing and cancer risk management in BRCA1/2 mutation-positive women aged 18–24. Health (London) 16 (6), 636–654.

Riley, B.D., Culver, J.O., Skrzynia, C., Senter, L.A., Peters, J.A., Costalas, J.W., et al., 2012. Essential elements of genetic cancer risk assessment, counseling, and testing: updated recommendations of the National Society of Genetic Counselors. J. Genet. Couns. 21 (2), 151–161.

Beran, T.M., Stanton, A.L., Kwan, L., Seldon, J., Bower, J.E., Vodermaier, A., et al., 2008. The trajectory of psychological impact in BRCA1/2 genetic testing: does time heal? Ann. Behav. Med. 36 (2), 107–116.

Schwartz, M.D., Peshkin, B.N., Hughes, C., Main, D., Isaacs, C., Lerman, C., 2002. Impact of BRCA1/BRCA2 mutation testing on psychologic distress in a clinic-based sample. J. Clin. Oncol. 20 (2), 514–520.

Hoskins, L.M., Werner-Lin, A., 2013. A multi-case report of the pathways to and through genetic testing and cancer risk management for BRCA mutation-positive women aged 18–25. J. Genet. Couns. 22 (1), 27–38.

Beth N. Peshkin
Georgetown University, Department of Oncology, Lombardi Comprehensive Cancer Center, Jess and Mildred Fisher Center for Hereditary Cancer and Clinical Cancer Genomics, Washington, DC, USA
Corresponding author at: 3300 Whitehaven Street, NW, Suite 4100, Washington, DC 20007, USA.
E-mail address: peshkinb@georgetown.edu.

Susan T. Vadaparampil
Moffitt Cancer Center and Research Institute, Tampa, FL, USA

Lindsey M. Hoskins
Lindsey Hoskins & Associates, LLC, Bethesda, MD, USA

Suzanne M. O'Neill
Northwestern University Medical Center, Graduate Program in Genetic Counseling, Chicago, IL, USA

James F. Barter
Women's Health Specialists of Montgomery County, PA, Holy Cross Hospital, Silver Spring, MD, USA

16 July 2015