Providing Care for Previvors: Implications for Oncology Nurses

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Previvors are individuals who are survivors of a genetic predisposition for developing cancer. They often are confronted with difficult decisions about management of risks that might include aggressive screening and prophylactic surgery. Psychosocial challenges exist for the affected individual, their partners, and offspring. Oncology nurses need to be aware of the complex and special needs of this ever-growing population.

A bout 10% of individuals diagnosed with cancer have a genetic predisposition, many of which can be detected with genetic predisposition testing (Weitzel, Blazer, MacDonald, Culver, & Offit, 2011). Once a mutation is identified in a family, other first-degree relatives have a 50% chance of also having the mutation.

The term “previvor” became a buzzword in 2007, and describes an individual who is a survivor with a genetic predisposition for developing cancer (Cruz, 2007). The public revelation by Angelina Jolie that she is BRCA positive and has undergone prophylactic mastectomies (PMs) has heightened awareness of the needs of previvors (Kluger & Park, 2013). Previvors represent an ever-growing population of patients with specific psychosocial and healthcare needs, and they need comprehensive and impartial information to help them decide how to manage this substantial risk.

Ideally, primary prevention strategies are used, which include prophylactic surgery and, sometimes, chemoprevention. Secondary prevention activities might include more aggressive screening than those recommended for people of average risk (American Cancer Society, 2013). Consequently, previvors often are confronted with complicated and emotionally charged decisions regarding management strategies (Tercyak, Mays, DeMarco, Sharff, & Friedman, 2012).

Case Study

Mrs. T is a 38-year-old married mother of an 11-year-old daughter and a 13-year-old son. She works part-time as a business manager in an auto parts company. At age 31, she tested positive for a known BRCA2 mutation, associated with a lifetime risk of developing breast cancer of about 90%, and a 45% risk of developing ovarian cancer (Lindor, McMaster, Lindor, & Greene, 2008).

Mrs. T was informed by the genetics professional about her lifetime risks for developing cancer and her options for surveillance, chemoprevention, and prophylactic surgery, both before testing and in follow-up sessions. She understood that her risk reduction for breast cancer would be more than 97% with PMs (Bevers et al., 2010; Zagouri et al., 2013), and she completed that at age 31 years, followed by immediate breast reconstruction with tissue expanders and implants. She has been undergoing pelvic examinations every six months with a gynecologic oncologist, CA 125 test, and pelvic ultrasound. She presents to the gynecologic oncologist to consider prophylactic salpingo-oophorectomy (PSO). She is informed that the risk for ovarian cancer would be reduced by as much as 96% if completed before age 45 years (Finch, Evans, & Narod, 2012).

Mrs. T also is informed that debate exists about the need for removal of the uterus at the time of the PSO because a small interstitial portion of the tube is left on the uterus in a PSO; however, few systematic reviews exist, and the risk of ovarian cancer appears similar to that of women who have a full hysterectomy (Gadducci, Biglia, Cosio, Sismondi, & Genazzani, 2010).

Management

Many previvors will initially manage risk with increased surveillance until the stress and worry about cancer risk motivates the individual to pursue prophylactic surgery (Hoskins, Roy, & Greene, 2012). The integration of the diagnosis of hereditary risk takes time, and subsequent decisions about prophylactic surgery often are influenced by previvor experiences with family members affected by cancer, experiences with prophylactic surgery, and whether they perceive their healthcare provider as genuinely concerned about their psychosocial needs and concerns (Hamilton, Williams, Bowers, & Calzone, 2009; Howard, Balneaves, Bottorff, & Rodney, 2011).
In the case of a positive BRCA mutation, these decisions can be particularly stressful and complicated for young women whose peers typically are confronting fewer and much less emotionally charged decisions (Hoskins et al., 2012). The plethora of negative opinions and reactions that these women face can be overwhelming and is in direct contrast to the support that many individuals encounter when diagnosed with cancer. The diagnosis is accompanied by varying degrees of stigmatization and opinion that regard prophylactic surgery as drastic. Stigmatization is accompanied by feeling isolated, being labeled, and feeling different from those who do not carry a mutation, even if the exterior appearance of the woman remains unchanged after prophylactic and reconstructive surgery (den Heijer et al., 2012).

Previvors who choose PMs make concessions. Despite advances, reconstruction is not perfect and requires a series of procedures that can take months to complete. Changes in body image are very real. Even if the woman does not appear different in clothes, she and her partner know her physical body has changed (Gopie et al., 2012). Not all women are satisfied with the cosmetic outcome. Most women report substantially less worry about developing breast cancer after surgery is completed, but it comes after the sacrifices and changes that accompany prophylactic surgery (Litton et al., 2009).

Support

Family members, particularly partners, can be a source of psychosocial support as previvors make test-related decisions (Tercyak et al., 2012). The importance of social support from family members should not be underestimated (DeMarco et al., 2010; Sherman, Kasparian, & Mireskandari, 2010). The impact of the diagnosis of a mutation can lead to significant psychosocial distress and stress for the partners as well. Distress is decreased in partners who are with the woman during both the pretest and disclosure meetings with the genetics professional (den Heijer et al., 2011). Better long-term adjustment may be associated with open communication with family members and partners (den Heijer et al., 2011). Encouraging couples to talk about their feelings may promote better adjustment and intimacy and, for this reason, couples are encouraged to attend counseling and physician appointments together.

One possible source of psychosocial support and education for previvors might include timely supportive information from Internet-based resources (Tercyak et al., 2012). Some previvors and their family members may prefer Internet-based resources to face-to-face psychosocial services and counseling because they offer anonymity when exploring sensitive topics, as well as providing direct access to factual information (see Table 1).

**Hereditary Risk**

Statistically, mutation carriers have a 50% chance of passing the mutation to the offspring. Many previvors have not yet completed their families and have to deal with the stressors of realizing they can pass the risk to subsequent children. In a study of 284 previvors, 44% experienced extreme worry about passing a mutation to subsequent generations (Staton, Kurian, Cobb, Mills, & Ford, 2008). Young previvors also need to consider whether they have PMs before or after childbearing is complete, which is challenging and associated with concessions; previvors must choose between breastfeeding and decreased worry about cancer risk (Hoskins et al., 2012). For single women, fears can occur about what a future partner may think about the decision to have PMs, and how to explain such decisions (Hamilton & Hurley, 2010). Many mothers choose surgery because they fear a premature death and leaving their children without a mother. The decision to have a prophylactic PSO means acknowledging that childbearing is complete.

A related issue previvors must address is when and how to discuss hereditary risk with their children (Tercyak et al., 2011). Parents may or may not convey information about risk of having a mutation accurately (Patenaude et al., 2013). Many parents are faced with the decision to tell children when a mother undergoes prophylactic surgery (Farkas Patenaude et al., 2012). The importance of honesty and

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**TABLE 1. Web-Based Resources for Previvors and Families**

<table>
<thead>
<tr>
<th>Agency</th>
<th>Resources</th>
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<tbody>
<tr>
<td>Bright Pink <a href="http://www.brightpink.org">www.brightpink.org</a></td>
<td>Provides resources and support for women with a hereditary risk for breast and ovarian cancer • Educational booklets in English and Spanish • Activities and educational programs for women at increased risk • One-to-one peer support</td>
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<tr>
<td>FORCE (Facing Our Risks of Cancer Empowered) <a href="http://www.facingourrisk.org">www.facingourrisk.org</a></td>
<td>Provides resources and support for previvors and women with hereditary breast and ovarian cancer syndromes • Online support • Local support groups • Mastectomy photo gallery • Education and publications • Spouse or partner support • Advocacy</td>
</tr>
<tr>
<td>National Society of Genetic Counselors <a href="http://www.nsgc.org">www.nsgc.org</a></td>
<td>Provides resources for patients and for healthcare professionals related to genetic syndromes • Searchable list of genetics professionals • Professional statements on issues related to BRCA testing</td>
</tr>
<tr>
<td>Sharsheret <a href="http://www.sharsheret.org">www.sharsheret.org</a></td>
<td>Provides resources and support for women of Jewish ancestry who have a genetic predisposition for developing cancer • Phone support • Local support groups • Education and publications</td>
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Cancer prevention and early detection for other cancers
- Colonoscopy starting at age 50 years and every 7–10 years
- Annual skin examination
- Tobacco elimination
- Regular use of sunscreen, protective clothing, and hats; minimize ultraviolet light exposure.
- Maintain body weight.
- Increase fresh fruit and vegetable intake; decrease fat intake.
- Increase intentional exercise to 150 minutes per week.

Management of bone health risks
- Counseling regarding the importance of daily weight-bearing exercise
- Bone density testing every one to two years starting at the time of the PSO
- Vitamin D 1,000 IU per day and calcium 1,500 mg per day

Management of peritoneal cancer risks
- Yearly pelvic examination to assess for peritoneal malignancies
- Discussion with provider regarding risks and benefits of CA 125 testing for peritoneal malignancies
- Counseling regarding subtle symptoms of primary peritoneal cancer

Menopause management
- Hormone therapy considered in eligible premenopausal patients with a balanced discussion of the potential risks and benefits
- Education about nonhormonal means to manage vulvarvaginal dystrophy
- Education about hot flash management and possible evidence-based methods of management

PSO—prophylactic salpingo-oophorectomy

FIGURE 1. Long-Term Follow-Up in Previvors With BRCA Mutations Following Prophylactic Surgery

Note. Based on information from American Cancer Society, 2013; Chapman et al., 2011; Finch et al., 2012; Gadducci et al., 2010; Kaplan et al., 2011; Matloff et al., 2009; Sturdee & Panay, 2010.

emphasizing that a mother is taking all steps to prevent future problems should not be underestimated. Parents may need assistance finding a balance between protecting and educating their children. For this reason, consultation with a genetics professional prior to disclosure is recommended to help parents consider the child’s maturity, potential approaches, words to use, and the importance of long-term open communication. Decision aids to assist with this procedure are available (Peshkin, DeMarco, & Tercyak, 2010).

In general, testing of adolescents is not recommended. Testing usually is completed at a point in which it would influence decisions regarding screening or prevention. Most adolescents do not need prophylaxis. Although many pediatricians and primary care providers will order genetic testing on adolescents if requested by parents, testing probably is best managed by a genetics professional who is experienced with genetic risk assessment pretest counseling (O’Neill et al., 2010). Genetic testing often is recommended by age 25 years, or 10 years before the first cancer diagnosis in the family because that is when surveillance would begin. Although many do test negative, for those who test positive, it can be frightening, particularly for younger women who do not have peers experiencing similar choices.

Conclusions

Mrs. T opted to have a total hysterectomy, including PSO, because she had two relatives who were diagnosed with ovarian cancer around age 45 years. She will require ongoing management of the side effects related to her prophylactic surgical choices (see Figure 1). Mrs. T was informed of the risks of premature menopause, including bone loss, vaginal dryness, and hot flashes (Matloff, Barnett, & Bober, 2009). Although she experienced relief and liberation in knowing she had taken all possible steps to prevent cancer, she did experience significant hot flashes and some vaginal dryness. The lifetime risk for developing peritoneal cancer is still at least 3%–4%, and long-term surveillance is needed (Chapman et al., 2011).

References


