# 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.

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About 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).