

Conditions and Consequences of a *BRCA* Mutation in Young, Single Women of Childbearing Age

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Young women (aged 18–39 years) who are at risk for hereditary breast and ovarian cancer (HBOC) because of a *BRCA1* or *BRCA2* mutation face a high risk of developing cancer before age 50 and a 50% chance of transmitting that risk to each of their children (Surveillance, Epidemiology, and End Results Program [SEER], 2008). By contrast, onset most frequently occurs from 62–79 years of age in women at average risk for breast cancer who do not have a family history of the disease (SEER, 2008). After discovering a personal high risk for HBOC, women are faced with a cascade of decisions for which they may have little preparation; the most wrenching can be whether to pursue prophylactic bilateral mastectomy and oophorectomy to manage their risk. For young women, the decisions pose special challenges related to sexuality, family and social relationships, reproductive choices, and achieving important vocational or other life goals. Young women with HBOC risk who also are single may face even greater difficulty in adjusting to their risk status in their efforts to establish intimate partnerships.

Background

Young adulthood is defined by Erikson (1963) to be from age 18–39. Challenges across young adulthood are seeking independence from parents, establishing gender identity, internalizing moral values, and examining career choices. Young adults typically are exploring intimate relationships while making childbearing, work, and lifestyle decisions (Newman & Newman, 2006).

Several sociologic, anthropologic, and psychological studies (Arnett, 1994, 1997, 1998, 2000; Perry, 1999; Schlegel & Barry, 1991) indicate that role transitions such as marriage, finishing education, beginning full-time employment, and becoming a parent are the important transition points into adulthood (Heckhausen, 1997; Schulz & Heckhausen, 1996). Successful navigation of adult development involves active pursuit of achievable goals and adaptive relinquishing of, or compensation

Purpose/Objectives: To explore the experiences of young, single women who are at increased risk for hereditary breast and ovarian cancer (HBOC) because of a *BRCA* mutation.

Research Approach: Qualitative.

Setting: Seven states and Canada.

Participants: 11 single women aged 18–35 years who tested positive for a *BRCA* mutation.

Methodologic Approach: Grounded theory with in-depth individual interviews conducted via e-mail or telephone.

Findings: Analysis resulted in three conditions and three consequences. Conditions were dating or not dating, time in a relationship, and physical impact of surgery or breast cancer treatment. Consequences were explaining their choices, experiencing a sense of urgency, and experiencing a sense of loss.

Conclusions: Young women who are at risk for HBOC face a complex array of decisions after finding out that they carry a *BRCA* mutation. Being single and childless adds to this complexity.

Interpretation: Nurses can listen to young women with HBOC risk, help them clarify their fears and understanding of their risk, and provide nonthreatening support that goes beyond simply providing more information and includes a nonjudgmental understanding of the young women's experience.

for, unachievable goals in the context of the shifting physical constraints of aging (Schulz & Heckhausen, 1996). For young women, the primary defining biologic constraint is reproductive capacity (Heckhausen, Wrosch, & Fleeson, 2001). Implicit in the decision about whether or when to manage risk by prophylactic surgery is whether to speed up volitional efforts to pursue childbearing (while managing anxiety about failure) or to relinquish childbearing and to gain acceptance of alternatives (e.g., adoption, childless lifestyle).

Young Americans have reported consistently that the transition to adulthood is characterized by an emphasis on individualism that includes accepting responsibility for oneself, making independent decisions, financial independence, and establishing a relationship with parents as an equal adult (Arnett, 1997, 1998, 2000, 2001). In