

# Women's Educational Needs and Perceptions About Survivorship Following Bilateral Mastectomy

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**Background:** More women are choosing to have a bilateral mastectomy to treat unilateral breast cancer despite it not being considered the standard of care. Women are making this choice for various reasons, including anxiety of follow-up screening of the other breast, risk of cancer recurrence for the rest of their lives, and desire to maintain control over the localized cancer. Currently, evidence-based information is lacking regarding this treatment choice. In addition, the concept of survivorship has yet to be examined in this population of women.

**Objectives:** This study aimed to explore women's educational needs and perceptions about survivorship following bilateral mastectomy as a treatment for unilateral breast cancer.

**Methods:** In-depth interviews were conducted with 23 women using a semistructured interview guide. Data were elicited, coded, and analyzed using thematic analysis.

**Findings:** Two themes were identified that addressed education and survivorship: "If they prepare you enough, you will know what to expect" and "I'm not a survivor yet." Women voiced their concerns about the inadequacy of information they received prior to and after surgery. Future research focusing on the specific educational needs of this population of women is warranted based on the increasing numbers of women choosing this treatment option.

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The number of women choosing to have a bilateral mastectomy following a diagnosis of unilateral breast cancer is on the rise, particularly for younger women (Dragun et al., 2013; Silva, Lapin, Yao, Song, & Sisco, 2015). According to Jerome-D'Emilia, Suplee, Boiler, and D'Emilia (2015), women are making this choice for several reasons, including anxiety of follow-up screening of the other breast, risk of cancer recurrence for the rest of their lives, and desire to maintain control over the localized cancer. Women who have bilateral mastectomies tend to be active participants in treatment decision making and often request detailed information from their healthcare team or from other sources. However, a dearth of evidence-based information exists specific to this treatment choice for unilateral breast cancer. In addition, the concept

of survivorship in this population has yet to be explored. Having a more thorough understanding of women's needs and expectations can improve the education, treatment, and follow-up for women undergoing bilateral mastectomy for unilateral breast cancer.

## Background

Gopie et al. (2013) found that a negative body image following bilateral mastectomy could be predicted by higher preoperative cancer distress, and this distress could be mediated with counseling and support prior to surgery. Although most studies have found that the majority of women who undergo bilateral mastectomy and/or reconstruction are satisfied with their treatment choice (Altschuler et al.,