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.