

# “It’s Like We Don’t Exist”: Tailoring Education for Young Women Undergoing Surgery for Early-Stage Breast Cancer

Alejandra Recio-Saucedo, PhD, Anthony W. Gilbert, BSc (Hons), Sue Gerty, BSc,  
Ramsey I. Cutress, BM, BCh, MA, PhD, FRCS, Diana Eccles, MB, ChB, MD, FRCP,  
and Claire Foster, PhD, CPsychol

**PURPOSE:** The implications of a diagnosis and consequent surgical treatment for breast cancer may be different for young women compared to older women. This study investigated the information requirements of young women to support their treatment decision making at diagnosis.

**PARTICIPANTS & SETTING:** A purposeful sample of 20 women diagnosed with breast cancer aged 40 years or younger who had undergone surgery and had participated in a large cohort study in the United Kingdom.

**METHODOLOGIC APPROACH:** Audio recordings of semistructured interviews were used to reveal information received at the time of surgical treatment.

**FINDINGS:** Themes identified were types of breast cancer, surgical treatments, nonsurgical treatments, fertility, and surgery and after surgery. Participants felt that information required throughout treatment was influenced by individual life circumstances, such as children or plans for children, relationships, and career intentions. Participants felt information was lacking on the effects of treatment on body image, reconstructive surgery, and genetic predisposition to breast cancer.

**IMPLICATIONS FOR NURSING:** Knowledge of the information requirements of young women diagnosed with breast cancer allows nursing staff to provide tailored support at times identified as most useful.

**KEYWORDS** breast cancer; young women; information needs; breast cancer surgery; decision making

**ONF, 45(2), 165–175.**

**DOI** 10.1188/18.ONF.165-175

In the United Kingdom, about 20% of breast cancer cases are diagnosed in young women. With about 1,100 deaths each year, it is the leading cause of cancer death for women aged younger than 50 years (Cancer Research UK, n.d.). Characteristics of breast cancer in young women as compared to older women include increased risk of recurrence, higher proportion of triple-negative cancers, and higher mortality rates, which present challenges to the treatment of breast cancer in this age group (Narod, 2012).

Randomized, controlled trials have demonstrated equivalent survival in suitable patients between those treated with mastectomy and breast conservation (lumpectomy and radiation therapy) (Fisher et al., 2002), and this appears to be no different in young women (Maishman et al., 2017), providing some women with a choice of surgical intervention to treat breast cancer. When presented with a surgical choice, however, women may struggle to make a decision because of lack of knowledge, individual decisional preferences, or emotional state after diagnosis (Molenaar et al., 2004; Nold, Beamer, Helmer, & McBoyle, 2000; Staradub et al., 2002). The difficulties of weighing pros and cons of different treatment options experienced by young women is counterbalanced by evidence suggesting that greater involvement in treatment decisions decreases decisional conflict and regret (Brown et al., 2012; Hack, Degner, Watson, & Sinha, 2006) and increases satisfaction with the decision (Janz et al., 2004). In addition, being informed about diagnosis and treatment can result in a positive impact on quality of life, greater satisfaction with choices, and improved ability to cope during and after treatment (Keating et al., 2010).

Elements involved in the treatment decision-making process include having sufficient information