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A preliminary study into women's experiences of undergoing reconstructive surgery after breast cancer

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A B S T R A C T

Breast cancer is the most common type of cancer among women. In Sweden, about 40% of women diagnosed with breast cancer undergo a mastectomy; breast reconstruction (BR) may be an option for these women. However, the experience of undergoing reconstructive surgery appears to be only very scarcely researched, despite its importance in clinical nursing.

Aim: The purpose of this study was to explore women's experiences of undergoing breast reconstructive surgery after mastectomy due to breast cancer.

Methods: Six women participated in narrative interviews about their experiences of reconstructive surgery, and the interview data were analysed using thematic narrative analysis.

Results: All six women were unprepared for the strenuous experience of undergoing a BR. They described the process as difficult and painful, entailing several operations and an unexpectedly long recovery period. They were also unprepared for how arduous it would be, both physically and emotionally. However, getting a BR had been important to all the women. The BR process was captured in four themes: (1) uninformed care; (2) arduous experiences; (3) body alterations; and (4) moving on.

Conclusions: Obtaining adequate information and being involved in the decision-making process along the pathway of a BR could help the women to prepare physically and emotionally for the strenuous experiences related to reconstructive surgery.

Introduction

Breast cancer is the most frequent type of cancer among women in Sweden, accounting for 29% of all cancer diagnoses (Cancerfonden, 2010). The primary treatment of breast cancer is either mastectomy or lumpectomy, with about 40% of women in Sweden undergoing a mastectomy (Malycha et al., 2008). The loss of a breast may lead to numerous feelings including mourning related to the cancer experience (Bjorkman et al., 2008), abnormality (Crompvoets, 2006; Hill and White, 2008), depression (Hill and White, 2008; Rolnick et al., 2007), and a loss of "wholeness" (Piot-Ziegler et al., 2010; Rolnick et al., 2007).

After a mastectomy, the options are to undergo a breast reconstruction (BR), to wear a loose prosthesis, or to do nothing to make up for the loss of the breast. Research shows that women choose BR because they want to get rid of the external prosthesis, feel whole again, regain femininity, and have fewer clothing limitations (Reaby, 1998; Shameem et al., 2008). Studies have also shown that women who choose a BR are significantly younger than whose who do not (Fallbjork et al., 2010; Reaby, 1998; Rowland et al., 2000; Shameem et al., 2008; Wehrens et al., 2005), have higher incomes (Alderman et al., 2011; Reaby, 1998), and are more likely to be white (Rowland et al., 2000). A recent Swedish study (Fallbjork et al., 2010) also found that women who had undergone BR rated the mastectomy as having a more negative impact on their feelings of attractiveness and body disclosure compared to their counterparts who had not undergone a BR.

BR is a term that describes a range of surgical procedures attempting to recreate a breast shape; this can be done immediately after the mastectomy or as a delayed procedure. The major techniques used for BR are implants, autologous tissue, or a combination of these two. The implant is usually placed below the pectoral muscle. When an expander implant is used, it is gradually filled with saline over several months (Ahmed et al., 2005; Djohan et al., 2008). There are a number of methods for using autologous tissue in BR, known as flap methods. The most common of these methods is to use either a section of the lower abdomen or the latissimus dorsi muscle. Fat, skin, and usually muscle are surgically removed and relocated to the mastectomy site to create a new breast (Fentiman and Hamed, 2006). Implants are much less

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invasive than flap methods, but they carry the risks of implant rupture or encapsulation, and the implants do not age with the woman's body. BR with autologous tissue leaves extensive scarring and muscle weakness at the donor site, but can provide a BR that is softer and more natural looking than implants. After the BR, a reconstruction of the nipple and areola can be performed (Djohan et al., 2008).

Regardless of the technique used, BR is still a major surgical procedure, often requiring consecutive operations to obtain a satisfactory outcome (Djohan et al., 2008; Harcourt and Rumsey, 2001). Women undergoing flap reconstructions may be surprised at the amount of scarring and the extensive period of recovery (Abu-Nab and Grunfeld, 2007; Lee et al., 2010). Pain and abdominal discomfort may last for up to two years after a flap reconstruction (Roth et al., 2007). However, most women are satisfied with the outcome of the BR (Brandberg et al., 2000; Nano et al., 2005; Nissen et al., 2002; Wehrens et al., 2005). Women in a Swedish longitudinal study undergoing various flap reconstructions perceived a positive change in life, feeling more "whole" and less uncomfortable in social situations after the reconstruction (Brandberg et al., 2000).

Contemporary research is chiefly concerned with the investigation of women's perception of the outcomes of different types of reconstructions in relation to quality of life and well-being (Brandberg et al., 2000; Nano et al., 2005; Nissen et al., 2002). In other words, the focus is on the effect of the BR on the women's life. Little, however, is known about women's experiences of undergoing reconstructive surgery.

Over the past four years, we have followed women in Northern Sweden who had a mastectomy due to breast cancer, focussing on their experiences of living without a breast and their reflections on BR. We conducted an in-depth interview study with 15 of these women, six of whom had undergone a BR. The strenuous experiences of reconstructive surgery narrated by these six women were vivid and touching. However, we were only able to locate a few qualitative studies (Abu-Nab and Grunfeld, 2007; Fang et al., 2010; Lee et al., 2010) related to women's experiences of reconstructive surgery. Studies from the UK (Abu-Nab and Grunfeld, 2007), Taiwan (Fang et al., 2010), and the USA (Lee et al., 2010) show that the women were unprepared for how difficult the recovery from their breast reconstruction would be, the magnitude of scarring (Abu-Nab and Grunfeld, 2007) and surgery (Lee et al., 2010), and the length of hospitalisation required (Fang et al., 2010). It is therefore important to broaden this area of research to include women's experiences of undergoing breast reconstructive surgery in Sweden too, even in a sample as small as our group of six women. The purpose of this study was therefore to explore women's experiences of undergoing breast reconstructive surgery after mastectomy due to breast cancer.

Methods

Context and participants

In 2003, 400 women in the Northern Region of Sweden were diagnosed with breast cancer, of whom 149 underwent a mastectomy. 149 women were identified by the Regional Centre of Oncology, Umeå University Hospital. In 2007, they were each sent a self-report questionnaire as part of a study investigating differences between women who had and had not undergone a BR. The response rate was 85% ($n = 126$). Of the responders, 25% ($n = 31$) had undergone a BR (Fallbjork et al., 2010).

In the questionnaire study, the participants were asked whether they would agree to take part in an interview later on; 56% of them answered yes. In order to obtain maximal variation (Polit and Beck, 2008), a strategic sample based on age, level of education, occupation, marital status, and breast reconstruction (yes/no) was selected. Hence, 16 women were selected in 2008 and invited by telephone to participate; all but one consented. Of these 15 women, six had undergone a BR and nine had not. The present study focuses on these six women's experiences of undergoing breast reconstruction.

In Sweden, equity in health care is an important goal (Johnsson and Sahlin, 2010). Health care is financed by public taxes, and so all people should be offered the same health care. Receiving a breast reconstruction should therefore be related to desire and biomedical considerations, and not to socioeconomic resources. The women in this study had their BR performed in various hospitals in Sweden. Reconstruction type varied, including both implants and flap methods, but all participants had delayed reconstructions. Several of the women had more than one reconstruction operation, due to complications and/or poor aesthetic results.

At the time of the interviews, the participants worked 75–100% of full time. Three were married, one was divorced but lived with a partner, one was unmarried but lived with a partner, and one was a widow. All the women were Swedish, and all had more than 10 years of education. Their median and mean age were both 49 years (range 39–61).

Data collection

The interviews were performed during 2008–2009 in a setting of the woman's choice; four chose to be interviewed in their own home, one in a hotel room, and one in a room at a university. The interviews were performed by a female researcher (first author), and lasted between 30 and 80 min (mean 51 min). All interviews were audio recorded and transcribed verbatim, and the transcriptions were validated against the recording. The interviews were carried out as a conversation between the participant and the interviewer. The larger interview study evolved around the opening question, "Can you tell me about the journey you have experienced since you found out that your entire breast would be removed?" For the six women who had undergone a BR, a substantial part of the interviews was related to their experiences of undergoing breast reconstructive surgery. These experiences were extracted from the larger text, forming a corpus of about 10 000 words. After each interview, the interviewer wrote reflective notes (Polit and Beck, 2008) including a summary and reflection on the women's experiences.

Data analysis

Thematic narrative analysis was used as described below (cf. Riessman, 2008). Each interview was read and reread in order to identify and code expressions of importance for each woman's story. The researcher's reflective notes were used to supplement each transcript. To secure the trustworthiness of the analysis, the authors independently extracted the text they found relevant, and these extractions were then compared and negotiated until consensus was reached among the authors. All interviews contained varied expressions related to four topics: deciding the type of BR, undergoing reconstructive surgery, experiences after the BR, and evaluation of BR. These expressions were then condensed and organised in a chronological manner into six short narratives about the experiences of undergoing a BR. Finally, the content of each topic was coded and compared across all six narratives, resulting in four themes. These themes are described in the Results section.

Ethical considerations

The participants were informed about the study orally and in writing. They were also informed that participation was voluntary,