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Aspects of body image after mastectomy due to breast cancer – A two-year follow-up study

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A B S T R A C T

Purpose: This 2-year follow-up study explores aspects of body image after mastectomy due to breast cancer.
Materials and methods: This population-based study included 76 women living in northern Sweden who, during November 2006 to October 2007, underwent mastectomy due to breast cancer. The women completed a questionnaire entitled "Life After Mastectomy (LAM)" 10 months after the mastectomy and again 2 years later. We used SPSS version 18.0 for data processing and analysis.
Results: The findings indicate that few significant changes in body image had taken place during the 2-year interval between the first and second completion of the questionnaire. An exception was a significant decrease in feelings of sexual attractiveness and comfort during sexual intimacy. At follow-up, 21% of the women had undergone breast reconstruction (BR). They were significantly younger than the women who had not had BR (53 vs. 63 years). Besides being younger, no other significant differences could be found between those women who had undergone BR and those who had not. The fact that the decrease in sexual attractiveness and feelings of comfort during sexual intimacy also applied to the subgroup of women who had had BR may therefore be surprising. A better understanding of issues related to breast cancer treatment and sexual function is vital.
Conclusion: It is important for health care professionals to be aware of problems related to sexual intimacy and to be prepared not just to provide information about these, but also to reflect on expectations vs. reality together with the women.

Introduction

In Sweden about one in nine women is expected to develop breast cancer during her lifetime. The mainstay of breast cancer treatment is surgery, an important treatment option for breast cancer since early Roman times (Yalom, 1997). Today, rather than removing the entire breast we use more sophisticated techniques of breast-conserving surgery. Besides surgery, additional treatment options include chemotherapy, radiation therapy and endocrine treatment, as well as combinations of these treatments, each of which has the potential to impact the woman's quality of life across several domains (Montazeri, 2008; Panjari et al., 2011; Salander et al., 2011). Because of new treatment regimes the survival rates of breast cancer have improved considerably, and in Sweden almost 80% of patients with breast cancer are still alive 10 years after diagnosis (The Swedish Cancer Society, 2012).

Even if surgery for breast cancer has been refined, many women undergo mastectomy. The rates of mastectomy vary between different countries. In Sweden about 45% of women with breast cancer undergo mastectomy, but there is considerable variation between different counties (Sandelin et al., 2012). The removal of the entire breast causes loss of symmetry, an obvious change in physical appearance, which also shows on the clothed body and bears an impact on clothing. These changes are shown to often bring practical and also emotional challenges (Wilmoth, 2001), challenges which the woman, on an everyday basis, has to deal with for the rest of her lifetime.

Contemporary research related to women living with breast cancer and its treatment has mainly focused on comparing various surgical procedures, i.e. mastectomy with/without breast reconstruction (BR) and breast-conserving surgery, as to their effects on quality of life (Engel et al., 2004; Falk Dahl et al., 2010; Harcourt et al., 2003; Nissen et al., 2001; Rowland et al., 2000) and/or body image (Collins et al., 2011; Fallbjork et al., 2010; Harcourt et al., 2003; Nano et al., 2005) and, to a lesser degree, sexuality (Karabulut and Erci, 2009; Montazeri, 2008). From the cross-sectional studies we have

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learned that different aspects of body image are of crucial importance for how the woman evaluates treatments and that radical surgery results in increased physical and emotional problems, as women undergoing mastectomy report greater concerns compared with women undergoing breast conservative surgery, especially with regard to dissatisfaction with appearance, body image and sexual function (Al-Ghazal et al., 2000; Anagnostopoulos and Myrgianni, 2009; Chen et al., 2012; Fallbjork et al., 2010; Gorisek et al., 2009; Rowland et al., 2000). The few prospective studies following a cohort of women over a 5-year period show similar results. Engel et al. (2004) followed a cohort of women undergoing mastectomy from the time of primary treatment to 5 years post-surgery and report that they continued to have lower body image and lifestyle scores, and were less sexually active compared with women with breast-conserving surgery (Engel et al., 2004). This has also been reported by Arndt et al. (2008) with regard to body image.

To provide further insight into the long-term impact of mastectomy on body image, the purpose of this follow-up study was to explore women's experiences after mastectomy due to breast cancer over a 2-year period. Areas of focus were their experiences of femininity, attractiveness to themselves and their partner, comfort with appearance, sexuality and relational comfort.

Materials and methods

Context

All women who underwent mastectomy due to breast cancer from November 2006 to October 2007 in northern Sweden were consecutively invited to participate in the study. During this time, 663 women were diagnosed with breast cancer and 148 (22%) of these underwent mastectomy. The women were identified by the Oncological Center (OC) at Umeå University Hospital, Umeå, Sweden.

Design and participants

The participants ($n = 148$) were recruited between August 2007 and June 2008, 10 months after the mastectomy (see Fig. 1), and were sent a questionnaire. At 10 months post-mastectomy they had completed the acute phase of treatment, including surgery and, where necessary, chemotherapy, and mostly also radiation therapy. A letter was attached to each questionnaire explaining the purpose of the study and assuring the women that participation was voluntary. Where the questionnaire was not returned within 2 weeks, the woman concerned was contacted by telephone. The participation rate at this first dispatch of questionnaires (T1) was 70% (104/148).

About 2 years later (i.e. about 3 years after the mastectomy), 95 of these 104 women were sent the follow-up questionnaire (nine women had died, according to the OC). The participation rate at this second dispatch (T2) was 85% (81/95). Because of >10% missing data in their questionnaires, five of the women were excluded, resulting in a total sample of 76 women. Socio-demographic and treatment characteristics at inclusion (T1) of the 76 participating women are presented in Table 1. The participating women did not significantly differ from the drop-out group as to age or other socio-demographic characteristics.

Instrument

In this study we used the "Life After Mastectomy (LAM)" questionnaire. This questionnaire has previously been tested for face and content validity (Fallbjork et al., 2010). The LAM questionnaire is a specific self-report questionnaire for women with breast cancer who have undergone mastectomy, and consists of four parts: part 1 includes socio-demographic questions (age, education, family status, employment) as well as treatment-related questions such as whether the breast was reconstructed or not. Part 2 includes the three single items from the European Organization for Research and Treatment of Cancer questionnaire, the EORTC QLQ-BR23, evaluating sexual interest, activity and enjoyment (items only measured at follow-up in this study). These EORTC QLQ-BR23 items are scored on a 4-point scale ranging from 1 ("not at all") to 4 ("very much") (Sprangers et al., 1996). Part 3 includes three questions investigating who or what influenced the decision for or against reconstruction (not investigated in this study); finally, part 4 consists of 15 items concerning body image after the mastectomy. These items are assessed on a 6-point scale ranging from 1 ("strongly disagree") to 6 ("strongly agree") (Fallbjork et al., 2010). Assessment of the stability (test–retest) of this part of the instrument was performed on a sample of 27 participants after a 2-week interval and resulted in a reliability coefficient of $r = 0.46$ (p-value 0.02). Tests regarding internal consistency (Cronbach's alpha) of part 4 of the instrument resulted in an alpha coefficient of 0.85.

Statistical analyses

Analysis was conducted using the Statistical Package for the Social Sciences (SSPS) version 18.0 (SSPS Institute, Chicago, IL, USA). The data were described using percentages, means (m) and standard deviation (SD). Comparisons between groups (BR vs. non-BR) were analysed using Pearson's chi-square test, Student's t-test and Mann–Whitney's U-test. The Wilcoxon signed rank sum test was used to compare differences between measurement T1 and measurement T2 (part 4 of the LAM questionnaire). Before the statistical analyses, seven items measuring body image (3, 5, 7, 9, 11, 13, 14) were reversed, with the implication that a higher score on the scale indicates a more negative impact. The scores for each body image item are presented as m and SD at T1 and T2. Bonferroni correction to adjust for multiple comparisons (Munro Hazard, 2005, p. 125), which resulted in a statistical significance at $p < 0.025$. To reduce internal drop-out and number of missing cases we imputed the mean value from each measurement for the BR and non-BR group separately (Shrive et al., 2006).

Ethical considerations

The participants in the present study received written information about the study. They were informed that participation was voluntary, and that they could withdraw from the study at any time. Measures were taken to ensure participants' confidentiality. All data were stored securely and only members of the research team had access to them. The study was approved by the Ethics Committee of the Faculty of Medicine, Umeå University.

Results

The Life After Mastectomy questionnaire (part 1) – socio-demographics and breast reconstruction

Among the 76 participating women no significant changes were found in living conditions and level of education between T1 and T2 (see Table 1). The 16 women (21%) who had undergone BR by T2 were significantly younger than the women who had not ($m = 53$ years, SD 11.6, vs. $m = 63$ years, SD 8.39; $p < 0.001$). There were no significant differences in living conditions, level of education and breast cancer treatment between the BR and non-BR group.