Journal of Plastic, Reconstructive & Aesthetic Surgery (2011) 64, 494–499

JPRAS
An International Journal of Surgical Reconstruction
www.JPRASurg.com

Patient satisfaction in relation to nipple reconstruction: The importance of information provision

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Received 16 February 2010; accepted 9 June 2010

KEYWORDS
Nipple reconstruction;
Satisfaction;
Information provision

Summary 127 women who had previously undergone surgical nipple reconstruction completed self-report questionnaires to assess body image, anxiety, depression, information preference, and satisfaction with surgical outcome, information provision, and the decision to undergo the procedure. Whilst most women were satisfied with the outcome of surgery and of their decision to have nipple reconstruction, this study highlights the importance of information provision that meets patients' needs at the time of decision-making, in particular information about likely nipple sensation after surgery.

Background

Breast reconstruction aims to offer benefits to breast cancer patients whose treatment includes mastectomy. To date, research in this area has included examination of patients' decision making about reconstructive surgery,[1,2] satisfaction with outcome,[3,4] the impact of reconstruction on body image and quality of life[5] and relationships and partners' experiences,[6,7] and comparisons of different surgical procedures and the timing of surgery.[8]

However, whilst there is a growing body of research into psychosocial aspects of breast reconstruction, very few studies have focused specifically on women's experiences of nipple restoration (by means of surgery or tattooing). Amongst the limited amount of research in this area, a survey[9] of 40 women reported satisfaction with the colour of their nipples after tattooing and 85% felt that the tattooing had improved their body image. Similarly, further research has also reported high levels of satisfaction with the colour, shape, size and overall outcome of nipple tattooing,[10] high levels of satisfaction amongst 14 women who underwent tattooing within a specialist nurse-led service[11] and in terms of nipple projection, sensation, colour, position and symmetry one year after completion of the nipple reconstruction (surgical or tattooing).[12]

In contrast, a recent study[13] reported that 24 women who had undergone prophylactic mastectomy were only

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doi:10.1016/j.bjps.2010.06.008

moderately satisfied with the outcome of nipple-areola reconstruction and considered this the least satisfactory part of the reconstructive process. They also found that satisfaction with the outcome of nipple reconstruction differed between patients and plastic surgeons, with patients being less satisfied. This study highlights the need to understand more about dissatisfaction with nipple reconstruction from patients' own perspectives.

However, there are a number of limitations with the existing research in this field, including small sample sizes and a reliance on study-specific questionnaires rather than the use of established and rigorously-tested measures of psychological outcome, including body image. Furthermore, whilst these studies have described patients' self-reported satisfaction, they have not explored what factors influence this satisfaction, nor have they explored the nature and extent of any regret that patients may have about their decision.

These issues have been examined in relation to breast reconstruction, where a study of 123 patients who had undergone a variety of breast reconstruction procedures[14,15] reported that poorer body image was associated with regret and dissatisfaction with their decision. Furthermore, since individuals vary in the type and amount of information they prefer,[16,17] Sheehan et al.[14] explored patient satisfaction with specific aspects of information provision and the extent to which this was related to their individual information needs. Whilst most participants were satisfied with the information they had received, they were least satisfied with written information and that which was available about sensations, outcome expectations, risks and side effects. Greater dissatisfaction with information was associated with regret about the decision to undergo reconstruction, as were higher levels of depressive symptoms. Since these issues have not been examined in relation to nipple reconstruction, the current study set out to explore body image and satisfaction with outcome, information provision and decision-making amongst women who had undergone nipple reconstruction.

Procedure

All necessary ethics and R&D approvals were obtained. 247 potential participants (women over the age of 18 who had undergone nipple reconstruction during a seven year period) were identified from hospital records and sent an invitation to take part in this study. This invitation consisted of a letter from their consultant, which outlined the study and enclosed a consent form, questionnaire and two stamped-addressed envelopes for the separate return of the completed consent form and questionnaire.

The questionnaire consisted of the following measures:

Demographic variables

Age, sex, education level, family status, ethnic background and their own, and their spouse's occupations were included.

Anxiety and depression

The Hospital Anxiety and Depression scale (HADS)[18] consists of 14 items, of which seven assess levels of depressive symptoms and seven measure anxiety. Potential scores range from 0 to 21 for both anxiety and depression, with higher scores indicating higher levels of distress. In the current study the internal consistencies were 0.84 for anxiety and 0.82 for depression.

Body image

The Body Image Scale (BIS)[19] was developed for use with breast cancer patients and consists of 10 items related to appearance and body image in relation to cancer treatment. Potential scores range from 0 to 30 with higher scores indicative of higher levels of body image distress. In the present study the internal consistency for this measure was 0.91.

Coping style

The Miller Behavioural Style Scale (MBSS)[17] measures individual preferences for information in response to physical and psychological stressors. Participants imagine four stressful situations and select up to eight strategies that they would use in each scenario. The MBSS has 2 scales (monitoring and blunting), but only the monitoring score was used in the present study, in line with Sheehan et al's study.[14,15] Potential scores range from 0 to 16 and those who report higher monitoring scores are deemed to have a preference for more detailed information. The internal consistency of the monitoring score in the present study was 0.67.

Information satisfaction

A seven item information satisfaction scale was constructed for the purpose of this study, based on a 9-item scale used by Sheehan et al.[14,15] in their study of regret following breast reconstruction. The seven items measured satisfaction with information overall, information about likely sensations after surgery, possible risk factors or side effects, the surgical procedure, and satisfaction with the format in which it was presented (picture format, orally and in print). Potential scores ranged from 7 to 35, with higher scores indicating greater satisfaction. The internal consistency for this measure was 0.88.

Reconstruction satisfaction

A seven item reconstruction satisfaction scale was constructed in the same format as the information satisfaction scale (see Figure 1), with total scores ranging from 7 to 35 and a higher score denoting a higher level of satisfaction. Items measured satisfaction with the nipple overall, appearance of the breasts both clothed and unclothed, and the size, shape, colour and sensation of the reconstructed nipple.

Decision regret

The Decision Regret Scale[20] consists of five items. Scores range from 1 to 100, with higher scores indicating higher levels of regret about the decision in question (in this