

Women's initial experiences of their appearance after mastectomy and/or breast reconstruction:
A qualitative study.

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Abstract

Objective: Surgical procedures intended to treat breast cancer or reduce risk of developing the disease typically result in changes to appearance and scarring of the breast area, and any donor sites. The longer-term impact of these changes on body image and quality of life are well documented, but research in this field has failed to explore women's initial experiences of their appearance after surgery. This study used a qualitative approach to gain insight and better understand the experiences of women at this time point in their treatment pathway.

Methods: Women ($n=128$) who had undergone mastectomy and/or breast reconstruction following a diagnosis of breast cancer or to reduce their risk of developing the disease completed an online survey. Open-ended questions asked participants about their experiences when seeing the post-surgical appearance of their breast/breast area (and donor site, if relevant) for the first time, and the support available to them.

Results: Thematic Analysis generated four key themes: 'preparedness and support', 'first thoughts and emotions', 'loss and grief' and 'the reaction of others'.

Conclusions: There was considerable variability in women's experiences. Some felt prepared and emotionally supported at this time, whilst others felt this element of care was missing. The findings suggest there is a need to ensure all women are informed and have the necessary support when looking at the results of their surgery for the first time. Areas for improvement were proposed, including pre-operative discussions, increased preparation and support. This could potentially contribute to better patient outcomes overall.

Keywords: Appearance, breast cancer, breast reconstruction, cancer, mastectomy, oncology, qualitative, scar, surgery.

Background

Over 80% of women diagnosed with breast cancer in the UK have surgery to remove the tumour: 43% of those undergo mastectomy whilst 57% opt for breast-conserving surgery (1). Many mastectomy patients opt for immediate or delayed breast reconstruction (2). In addition, growing numbers of women are electing surgery to reduce their risk of developing the disease. These procedures are all likely to result in changes to appearance such as breast size and shape, complete removal of one or both breasts (3) and scarring to the breast area and, for some reconstructive techniques, donor-sites elsewhere on the body (4).

To date, a sizeable body of quantitative and qualitative research has focussed on the longer-term and ongoing psychosocial and emotional impact of an altered appearance following treatment for breast cancer, including poor body image, depression and anxiety, sexual functioning difficulties and impairments in overall quality of life (3,5–7). Numerous qualitative studies have vividly described how changes to appearance can have an enduring negative impact. For example, Manderson & Stirling (17) reported one participant “*walking around feeling like an absolute monster*” (p85) whilst another woman described “*when you look in the mirror and see this one-breasted creature*” (8) (p88). However, research also highlights positive reactions, with some participants describing satisfaction with scars and the aesthetic outcome: “*this has been done nicely ... yes, it is tight, really very tight: very beautiful.*” (9) (p1618) and perceiving their scars as symbols of triumph, “*...my war wounds of life*”(10) (p1485). Yet, whilst the focus of these studies

has been on longer term outcomes, there is a distinct lack of research into women's initial experiences of seeing the early post-operative results of breast cancer-related surgery.

An understanding of women's experiences and the support they need/receive at this time point is needed if health professionals are going to adequately prepare patients, pre-operatively, for the post-operative changes to their appearance. NHS guidelines (2) stipulate that specific information about scarring (likely position, length and any donor site) should be provided and discussed in detail with patients considering breast cancer surgery, in order to help them make an informed decision about their treatment options and manage expectations (2). However, despite these guidelines, many women report being dissatisfied with the pre-operative information they received about the likely appearance of their post-surgical scars (2). This is important given the findings of a meta-analysis which demonstrates how patients' pre-surgical expectations have a robust association with postsurgical outcomes and quality of life (11).

Research in the field of burns injuries has found that patients' first experiences of seeing their altered appearance is distressing and may impact subsequent psychosocial adjustment and have long-term negative consequences (12). However, to our knowledge, no qualitative research has focused expressly on women's initial experiences of seeing their appearance for the first time after mastectomy and/or breast reconstruction. Consequently, the objective of this study was to gain insight into women's initial experiences of seeing their appearance. The study used open-ended questions and thematic analysis to capture the richness of language provided within the participants' responses and explore their experiences at this previously neglected time-point. The findings may potentially inform treatment pathways and improve the provision of care by identifying women's support needs prior to and immediately after surgery.

Method

Participants and procedure

The data reported in this paper was collected within a large mixed methods study (*reference not included for purpose of blind peer review*). Women aged 18 years and older, fluent in English and who had undergone a mastectomy with/without immediate reconstruction or delayed reconstruction following a diagnosis of breast cancer, DCIS or at a high risk for developing breast cancer were eligible to participate. At least six months must have passed since surgery, so as not to place an additional burden during this sensitive time. 149 women were recruited from across the UK to participate in an online survey. 21 women were excluded from analysis as they did not meet the eligibility criteria. This resulted in a sample of 128 participants who had undergone mastectomy and/or breast reconstruction. Participants provided informed consent online prior to completing the survey.

The majority self-identified as White ($n = 117$), ranging in age from 31-74 years (mean = 51.60 years; $SD: 10.68$). Table 1 displays participants' characteristics and treatment details. Women were recruited from various breast cancer charities and organisations including Breast Cancer Care (www.breastcancercare.org.uk) and After Breast Cancer Diagnosis (www.abcdiagnosis.co.uk), through their online forums, newsletters, bulletins, websites and social media. Further participants were recruited through the social networking sites and website of the authors' research group. Ethics approval was obtained from the authors' institution.

{INSERT TABLE 1 HERE}

Design

The questionnaire was hosted securely online by Qualtrics.com and the study design and survey questions were based on research into burns patients' experiences of seeing the results of their injury for the first time (12). These were adapted to suit our particular patient population, with specific questions about any donor site and additional free-response questions (Table 2). Two patient representatives with personal experience of mastectomy and breast reconstruction provided feedback on the survey, and the wording to some questions were edited as a result of their advice.

Given the sensitive nature of the subject, the questionnaire allowed participants to complete their responses in their own time and in a place of their choice. This anonymity may have enabled participants to provide more personal and detailed responses than they may have shared in an interview or focus groups. Participants were provided with a free-text box to respond to open-ended questions in relation to their first surgical procedure rather than follow up or revisional procedures. Questions covered recollections of their emotions and expectations, and the support they needed and/or received (see table 2).

Table 2

Free response questions included in the survey.

(1) Please describe the feelings or emotions you had when you saw your breasts/breast area for the first time.

(2) What were your concerns/expectations about looking at your breast/breast area for the first time?

(3) What thoughts or images went through your mind?

(4) Is there anything else you would like to tell us about your experience of seeing the appearance of your breast surgery for the first time?

(5) Is there anything else you would like to tell us about your experience of seeing the donor site for the first time? (if relevant)

(6) Please describe what help, if any, you were offered about looking at your breast/breast area.

(7) What, if anything, could have been done differently by the breast care service to improve your experience of looking at your breast surgery for the first time?

Analysis

Data were analysed qualitatively using inductive Thematic Analysis (TA), chosen for its flexibility to various epistemological stances. An essentialist epistemology was chosen as this supports the aim of exploring participants' experiences (14). The initial thematic analysis was conducted by the first author using Braun and Clarke's 6-step model (14). This involved (1) data immersion and anonymisation, (2) data coding, (3) analysing the codes in isolation to purposefully identify themes, (4) relating thematic material back to coded data extracts to ensure they were coherent, (5) clearly defining and naming themes, and (6) writing up the results. Whilst conducting the analysis the first author was aware of personal experiences of having closely witnessed the impact of breast cancer on the lives of friends and their families. Although this was felt to provide valuable insight, it was recognised her experiences may have influenced the analysis. Consequently, the themes were discussed at length and validated by all contributing authors by checking the quotes and themes to ensure they were coherent.

Results

The data collected in this research suggests a range of complex emotions and a dichotomy of experiences when women saw their appearance after breast surgery for the first time. Analysis generated four salient themes evidenced across the participant group: preparedness and support, first thoughts and emotions, loss and grief, and the reaction of others. Each theme is outlined below, with a selection of representative quotes from participants.

Theme 1: Preparedness and support

This theme encapsulates the variation in women's reports of preparation and the provision and need for support when looking at the results of their surgery for the first time. Some described having received excellent professional and familial support - *"Nurses encouraged looking at it in own time scale and understood reluctance. They were very supportive"* (50, mastectomy). However, for others, this element of care was absent and the failure by hospital staff to prepare, manage expectations and offer support led to very varied experiences. In some instances, participants were provided with a comfortable and private space, whilst others expressed how a lack of privacy had rendered the experience more traumatic - *"Needed more privacy. Patients on the ward and visitors could hear all that was said"* (65, mastectomy and delayed reconstruction). Additionally, some women were provided with relevant literature *"The specialist plastic surgery nurses had shown me images of other reconstructions before I had my surgery"* (55, mastectomy, immediate reconstruction), however, this contrasted with others who reported that this was not provided.

A number of women reported having resorted to searching for information on-line, where images were often distressing. This had consequently made the process even more difficult, *“I had looked online and seen some horrific images, lumpy, untidy, really scary scars”* (53, mastectomy, delayed reconstruction). Others who had received information and support nevertheless expressed shock at the results of their surgery - *“...nothing prepares you for the hideous scar and the other breast hanging there like a useless lump of meat”* (45, mastectomy).

Some recalled being unaided at this time and described how this had made the experience more distressing - *“I was not offered any help ... the ward nurses were far too busy dealing with other patients”* (49, mastectomy, delayed reconstruction). Yet others voiced how they did not need any support, wanting privacy and choosing to be alone at this time - *“It was a purely private moment. I would have hated anyone else being present when I looked”* (46, mastectomy).

Theme 2 – First thoughts and emotions

This theme captures the variations in women’s reports of their initial emotional reactions to physical changes after surgery. For some, this was a highly charged and emotional experience which brought to the forefront a number of strong sentiments - *“Scared. Frightened. Had anger issues. Hated people”* (55, mastectomy, immediate reconstruction), whereas others were pragmatic and viewed it as part of the process - *“Didn’t really give it much thought”* (34, mastectomy). A number of women described valuing their health and being free of cancer more than the aesthetic appearance of their bodies - *“It was the cancer that mattered, not society’s expectation of how a female should look”* (47, mastectomy). This contrasted with others who were horrified at their appearance - *“When I first looked at mine, my body reminded me of a boxer’s*

face with a swollen stitched up eye” (49, mastectomy). A number of the women used dramatic analogies and powerful, emotive language to describe their appearance - “...like Frankenstein – somehow normal and hideous at the same time” (56, mastectomy, immediate reconstruction).

Whereas some women were shocked and devastated by their altered appearance, others were pleased with the result of their surgery and their appearance was better than they had expected - *“After the reconstruction there was relief, joy, pride in the amazing job, I could have shown the world. I was just so happy to have a breast form again.” (55, mastectomy, delayed reconstruction)*

Some highlighted a positive element to the experience: *“I was pleased to see the back of the ‘extra’ tummy I had after two caesarean births and felt pleased it had been put to good use! It felt like my precious children had a hand in me being able to use my own tissue to create breasts” (53, mastectomy, immediate reconstruction).*

A number of women who had had autologous breast reconstruction described the appearance of their donor site. For some, the position of this scarring was less visible than the breast area which lessened the impact - *“Given that the scar is on my back it’s not something I see regularly” (40, mastectomy, immediate reconstruction)*

and others were so pleased with the results of their breast reconstruction that the donor site appearance was not of importance - *“So delighted to have the reconstruction couldn’t care less about the donor site” (65, mastectomy, immediate reconstruction).* However others were shocked by the appearance – *“It looked like they had carved my back up” (55, mastectomy, immediate reconstruction).*

Again, this highlights the variability in women’s experiences and reactions at this time. Some women were pragmatic and viewed the removal of their breast(s) as a necessary procedure in the

treatment process and valued their survival as more important than the aesthetic result. Conversely, whilst some were horrified at their appearance, others were pleased with the results.

Theme 3 - Loss and grief

This theme describes women's sentiments of loss and grief at the removal of their breasts. The representation of the breast as integral to feminine sexuality was apparent to some and its removal reflected the loss of feminine identity - "*I had lost my femininity and part of my identity*" (50, *mastectomy, delayed reconstruction*). The loss of symmetry and the implications this had was evident to some who had undergone mastectomy without reconstruction. They described how the awareness of their physical imbalance created a heightened sense of loss - "*I felt lopsided, so strange with one boob hanging*" (49, *mastectomy*). A sense of loss was also apparent in women who had undergone mastectomy with immediate reconstruction, despite the surgery aiming to restore the breast shape and represent the female physical form - "*Sadness to have lost a part of me*" (55, *mastectomy, immediate reconstruction*). Physical loss and perceived loss of femininity was often apparent in women's responses, as was the need to adapt and accept the new physical self.

However, others did not view the breast as essential, and expressed gratitude that the cancer had not affected a more critical part of their body. The physical loss became superfluous, similar to how survival had outweighed aesthetic appearance in earlier themes - "*...was grateful that if I had to have cancer it was in a part of my body that I didn't actually "need"*" (57, *mastectomy*).

Theme 4 – The reaction of others

The final theme focused on how women were concerned about the reaction of others and, for some, prioritised the welfare of others above their own wellbeing at this emotional time - "*I felt I had to*

be brave for my family. For my husband, my children and my parents” (51, mastectomy, immediate reconstruction). A number expressed concern about the reaction of others, especially their husband’s reaction to their appearance after surgery and how their altered appearance might negatively impact their intimate relationships. The sense of feeling unattractive in both the short and long term was evident throughout - *“Like most women I was very scared, and still am, that my husband would no longer fancy me” (51, mastectomy, delayed reconstruction).*

The reactions of others were not only a concern amongst respondents who were in relationships. Those who were not in a partnership at the time of the survey reported similar worries and anticipated a negative reaction from others in the future - *“Being a single parent I was more concerned of my appearance for future if I met someone.” (41, mastectomy).*

These concerns were also not confined to family and friends. Some women were anxious that their altered appearance would be noticeable to others and feared being judged, which led to a sense of shame and embarrassment - *“...would other people notice the area looked small, hard and not quite in the ‘right’ place” (56, mastectomy, immediate reconstruction).* Some referred to how they would manage this situation by disguising their appearance with clothing - *“I will look alright with my clothes on – no one will be able to tell” (53, mastectomy, immediate reconstruction).*

Discussion

To our knowledge, this is the first qualitative study to explore women’s initial experiences of their appearance after breast cancer surgery. A key finding, as in previous research (4,13), was the variability of experiences and disparity in support provided for women when seeing the results of their surgery for the first time. Whilst this was a positive experience for some, others reported

considerable distress and disappointment. A recent meta-analysis (11) highlighted the role of patients' expectations in predicting postsurgical outcomes and underlined the need to ensure they are realistic in order to improve postoperative quality of life and satisfaction with care. Our study supports these findings. Scarring, including donor site scarring, was also a concern for many of the women. This supports findings which reported this as an area of dissatisfaction with women undergoing reconstructive surgery following mastectomy (4).

Our data suggests a lack of preparedness and support could increase distress at this sensitive time. Women who reported feeling better equipped in advance, described not being rushed into looking at their appearance for the first time and valued the presence and support of someone being with them. This is in line with research with women post-mastectomy which revealed the need for healthcare providers to consider the psychosocial well-being of patients both pre and post operatively (15). Although some women in the current study were satisfied with the level of information and support they received, others felt this element of care was lacking. There is an evident need to consider individual differences and tailor support at this time in order to meet women's needs accordingly. Areas for consideration include the content and mode of information provision, and a discussion around preferences for having others present (for example, a partner, breast care specialist).

Whilst much research to date has focussed on the long-term impact and reactions to breast cancer scarring (8,10,16) this study highlights the impact of patients' 'initial' reaction to their appearance after surgery. The variety in women's responses of their experiences was evident in each surgical group. The vivid and compelling language used by many women to depict their breasts was also evident in previous qualitative studies (17). For some participants, survival was emphasised over aesthetics – again supporting previous research (10).

In line with other findings (18), the physical loss of the breast represented a loss of identity and femininity for some women, and they reported feelings and sentiments of grief - captured in the theme “loss and grief”. This emotional reaction post-surgery has been identified within other patient groups including prostate cancer and diabetic patients following limb loss and amputation (19,20).

The women in this study frequently placed the reactions of others, particularly husbands and partners, above their own health and wellbeing, illustrated in the theme “the reaction of others”. This mirrors findings from a study which found that some women prioritise the needs of their family, especially children, above their own needs following a diagnosis of breast cancer (21).

Participants often voiced concerns regarding how surgery impacted their sexuality and body image, paralleling findings by Manganeillo and colleagues (23) who explored quality of life amongst breast cancer patients post mastectomy. Similar to the findings of a meta synthesis (22) we found that breast cancer surgery frequently affected women’s sexual functioning and how they believed they were perceived by others, especially husbands and partners. This may be due to the breast being inherently associated with societal expectations of femininity and womanhood (23). The Sociocultural Model (24) offers one potential explanation for these findings. It proposes that individuals feel pressure to meet societal ideals of appearance/beauty and their satisfaction or dissatisfaction with their body is based on the extent to which they perceive themselves to meet these ideals. For women, these include having unscarred breasts of equal size and shape. Breast cancer surgery often results in an altered appearance which opposes these ideals, such as scarring. Negative reactions from the women in this study towards their initial appearance after breast cancer surgery could be a consequence of their perception that their breasts do not meet the idealised images to which they aspire. Future research could explore the application of this theory further

and suggests a possible component of intervention to support women who are negatively affected by an altered appearance after breast cancer surgery.

Limitations

Several limitations to this study are acknowledged. First, it does not include women who had undergone breast conserving surgery. Future research should include these patients in order to gain a fuller picture of first impressions of post-surgical results. Second, the participants were all recruited through support organisations - the experiences of those who are not in contact with such organisations might be different. A further limitation is the retrospective design, and the time since surgery ranging from six months to more than 11 years which may risk recollection bias. Prospective, longitudinal research is needed to fully understand women's initial experiences of their post-surgical appearance, and examine its potential long-term impact on quality of life, adjustment and body image. This would help guide how to best prepare women at this key point in their treatment pathway. Additionally, most of the women described their ethnic origin as white and future research should explore the experiences and support needs of women from ethnically diverse populations. Future research would benefit from conducting face-to-face interviews to explore women's experiences in more detail. Finally, the findings do not reflect men's experiences with breast cancer surgery and research with this group would enrich the field further.

Clinical implications

There is a clear need to prepare patients for seeing the results of surgery for the first time. Managing their expectations of what they will see is important and identifying and addressing appearance concerns before as well as after surgery could improve patient experiences. In

accordance with the theme “Preparedness and support”, pre-operative information and discussions with patients should include where, when and how they can expect to see the results of surgery for the first time and could potentially benefit patient satisfaction and outcomes. Postoperative support should include a preparatory discussion, privacy and a supportive presence (staff and/or family member/partner) tailored to individual needs.

Conclusion

This study has highlighted variation in women’s experiences of seeing the results of breast cancer surgery for the first time, and the emotional and psychosocial impact this can have. Preparing women for this event and offering support in response to individual needs could potentially contribute to better patient outcomes overall.

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Ethical approval for this study was granted by The University of the West of England on 12th May 2017, reference number: UWE REC REF No: HAS.17.04.133.

Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Table 1

Sample characteristics and treatment variables (n=128)†.

Characteristic		N	%
Ethnicity (n=127)	White	117	92.1
	Mixed background	4	3.1
	Black/Black British	2	1.6
	Other	3	2.4
	Prefer not to say	1	.8
Relationship Status (n=128)	Single	12	9.4
	Married	94	73.4
	In a relationship	10	7.8
	Divorced	8	6.3
	Separated	3	2.3
	Widowed	1	.8
Surgical procedure (n=128)	Mastectomy	49	38.3
	Mastectomy and immediate breast reconstruction	47	36.7
	Mastectomy and delayed breast reconstruction	24	18.8
	Other ††	8	6.3
Time since first surgery (n=128)	6 - 12 months	32	25
	1 - 2 years	32	25
	3 - 4 years	27	21.1
	5 - 6 years	13	10.2
	7 - 8 years	7	5.5
	9 - 10 years	10	7.8

	11 + years	7	5.5
Reason for surgery (n=128)	Diagnosed with invasive breast cancer	91	71.1
	Diagnosed with Ductal carcinoma in situ	26	20.3
	To reduce risk of developing breast cancer in the future	2	1.6
	Not known	9	7
Specific reconstructive procedure Undergone (n=69)	TRAM Flap	3	4.3
	DIEP Flap	18	26.1
	Latissimus Doris Flap	15	21.7
	Implant	25	36.2
	Not known	6	8.7
	Unsure	2	2.9
Currently undergoing treatment (n=128)	Yes	52	40.6
	No	76	59.4
Treatment currently undergoing (n=52)	Hormonal	39	75
	Chemotherapy	5	9.6
	Radiotherapy	3	5.8
	Other	5	9.6

†When totals do not account for 100% this is due to non-respondents.

†† These patients appear to have selected 'other' because they wished to write a more comprehensive answer, but all included 'mastectomy' in their description and therefore fit the criteria.