

Body Image after Mastectomy: A Thematic Analysis of Younger Women's Written

Accounts

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RUNNING HEAD: BODY IMAGE AFTER MASTECTOMY

Abstract

This study investigated younger women's body image after mastectomy. Forty-nine women, aged 29-53 years (mean age 39 years) who had had bilateral (n = 8) or unilateral (n = 41) mastectomy responded to open-ended questions online. Inductive thematic analysis revealed that aesthetics were less important than survival between diagnosis and mastectomy. Following mastectomy, women negotiated new body identities. Treatment effects such as weight gain were significant concerns. However, impacts on body confidence varied, and some participants rejected mainstream body-shape ideals and reported feeling proud of their scars. Implications for supporting younger women post-mastectomy, including promotion of body acceptance, are discussed.

Key words: mastectomy, body image, thematic analysis, identity, weight gain, confidence.

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Breast cancer is the most common cancer affecting women (Cancer Research UK, 2015a), and each year, around 50,000 women in the UK are diagnosed with breast cancer

(Macmillan Cancer Support, 2015). Surgery is currently an important part of the treatment pathway, involving either breast removal or breast-conserving lumpectomy (Urban and Rietjens, 2013). Mastectomy involves removal of one or both breasts (National Cancer Institute, 2015) and tends to have relatively minimal physical complications; physical recovery from mastectomy usually takes about three to six weeks (National Health Service, 2015). However, psychological impacts may be more negative (Thomas et al., 2002) and may include body dissatisfaction and feelings of lack of sexual attractiveness (Baucom, Porter and Kirby, 2006; Brandberg et al., 2008). This study investigates younger women's accounts of body image following mastectomy.

Although currently 80% of breast cancer diagnoses are in women over 50 years, around 9800 women under 50 are diagnosed with breast cancer each year in the UK (Cancer Research UK, 2015). Research has shown that mastectomy impacts on young women's body image, threatening sense of worth and desirability, and may lead to avoidance of sexual relationships (Baucom et al., 2006). Medical teams tend to assume that reconstruction will necessarily impact positively on young women's body image and aid recovery, and the UK National Institute of Clinical Excellence (NICE, 2011) new quality standard QS12 suggests that all women with early-stage breast cancer who are to undergo mastectomy should be informed about reconstruction. It has also been argued that individual women may be put under pressure to have reconstructive surgery to conceal breast loss (Rubin and Tanenbaum, 2011).

In order to plan treatment pathways, it is important to understand younger women's body image following mastectomy. However, there is relatively little existing research on impacts of mastectomy and breast reconstruction on younger women's body image. This is an important omission, particularly given relatively high survival rates in younger women compared with other cancers (Cancer Research UK, 2015b). Also, although researchers have

tended to assume that impacts on body image will be completely negative, mastectomy may be experienced in complex ways, some of which may not be entirely negative (Altschuler, Nekhlyudov and Rolnick, 2008; Denford et al., 2011), so it is important to use women's own accounts to ground the analysis. This is another area where research is scarce, and there are currently few studies where younger women explain their experiences of mastectomy in their own words (Holland, Archer and Montague, 2014). This study sought to address these two issues by focusing on accounts of body image after mastectomy in younger women.

The Current Study

This study set out to examine both positive and negative impacts on body image, as described by the women themselves, and focused in particular on younger women (aged 45 years or under at diagnosis) who have been underrepresented in research on women's experiences of mastectomy in the past (Holland, Archer, and Montague, 2014).

Research Question: What are the impacts of mastectomy on younger women's body image?

Method

Design

To achieve insight into younger women's body image following mastectomy, a qualitative approach was adopted, focusing on the experiences of women aged 45 or under at the time of diagnosis with breast cancer. To encourage disclosure and ensure that women felt comfortable discussing their experiences, we asked them to complete a series of open-ended questions anonymously through an online questionnaire. The exploratory nature of the research provided the chance to gain detailed insight into their experiences.

Recruitment

To ensure that we accessed the views of a wide range of younger women who had experienced mastectomy, women were invited through a UK-based online support network. This network is only open to any young woman with a diagnosis of breast cancer, and the second author is a member of this online group. The group is promoted through other forums such as Breast Cancer Care online chat forum and in UK hospitals and is open to those with a diagnosis of primary breast cancer and those with secondary cancers. The network is available through an online popular social media platform where those who wish to join send a message to the administrators with information about their diagnosis. The group is private, and is only for those who have had a diagnosis of breast cancer, so does not include those who are taking prophylactic measures without evidence of the disease. To be included in the sample, women had to be between 19-45 years old at the point of diagnosis with breast cancer. A message was put on the site by the group administrator, informing members that the research team were recruiting participants to complete an online questionnaire looking at the experiences of women who have undergone mastectomies for breast cancer. Women were told that the study had received ethical approval, and were given a weblink for the research.

Participants

Forty-nine, English-speaking women aged 45 or under at time of diagnosis with breast cancer (mean age 39 years, range 29-53 years) who had had bilateral ($n = 8$) or unilateral ($n = 41$) mastectomy were recruited from one UK-based online support group (see above). We did not ask women to state their job status. Forty-one women self-identified as White British, two as White Irish, two as White Other, and four did not respond to the question. Eleven had not yet completed medical treatment. Of those who had finished treatment, twenty women had had mastectomy less than a year before questionnaire completion, fourteen 1-2 years before, one 3-5 years, and three 6-10 years before. Of those who responded to the question, twenty-one from the forty-nine women had had no breast reconstruction at the point of completing the

questionnaire. Of those who reported having had breast reconstruction, sixteen had immediate, and five delayed reconstruction.

Materials

A semi-structured schedule was constructed using previous literature surrounding breast cancer and mastectomy as a guide. Due to the exploratory nature of the research, the two questions on body image were kept broad to allow women to share their thoughts and experiences. As part of a series of open-ended and closed-ended questions asking about choices concerning breast reconstruction, demographics, illness, and treatment-pathways, women were also asked two key body image-related questions; “In addition to the removal of the cancer, please share with us what was important to you when you were advised or decided (prophylactic) to have one of both of your breast removed”, and “How do you feel about your body image currently, has this changed since diagnosis and if so how has it changed?”

Procedure

Ethical approval was first gained through Manchester Metropolitan University ethics committee. The initial post from the website administrator gave participants a link to an anonymous *Qualtrics* questionnaire. All women gave their informed consent to taking part in the study, including the use of anonymised quotes in reports, through ticking a box on the online questionnaire to confirm agreement. At the end of the questionnaire, women were also given the contact details (telephone and e-mail) for the second author to enable follow up if they had any queries or wanted more information about the study. After data were analysed, the resulting paper was made available to all participants through the original website, and they were encouraged to send us their comments

anonymously through *Qualtrics*. *Although we are helping Jayne to recruit to this study we are not responsible for the research. Any queries and questions regarding participation must be directed to Jayne directly, her details are in the link. Also just to remind you all that that all research requests must be made to Edna directly rather than posted on the groups as we need to ensure that they are legitimate and that they have received either university or NHS ethical approval. Many thanks* Although we are helping Sarah and Jayne recruit to this, we are not responsible for the research. Any queries or questions regarding participation must be directed to Jayne directly, her details are on the link. Also just to remind you all that research requests must be made to Edna directly rather than posting in the groups as we need to ensure that they are legitimate and that they have received either university or NHS ethical approval.

Data Analysis

Women provided between one (3 words; "I hate it!") and twelve lines (179 words) of text in answer to each question, with an average of five lines of text. Braun and Clarke's (2006) thematic analysis approach was employed in data analysis to identify themes related to body image following mastectomy, capturing women's understandings, and allowing an in depth analysis of the data. Data were described, summarised, and then interpreted in relation to broader implications. The first author, who is a health psychologist with experience of research on body image familiarised herself with the data by reading responses several times, whilst taking notes. Points of interest were noted whilst reading and re-reading the transcripts. Following production of an initial set of codes, a thematic map was produced which presented themes and sub-themes. Accounts were then re-read to ensure that coding

was checked, and that nothing had been overlooked. Themes and sub-themes were then named. The second author, who has a personal diagnosis of breast cancer with mastectomy and reconstruction and research interests in representations of the female form, cross-checked the set of themes and was involved fully in their interpretation and write-up for dissemination. Both authors engaged in reflexive analysis throughout the process of analysing the data, following Willig (2008). When we gave participants the opportunity to comment on a previous draft of this paper anonymously through *Qualtrics*, one respondent sent us helpful comments where she noted that we had relied too heavily on quotes from one participant in the paper (we have rectified this in the section below in response to her concerns), but that she was “happy enough with the quotes and discussion”. No other participant chose to comment although eight accessed the paper.

Results

Inductive thematic analysis revealed four key themes that were evidenced across the participant group. In the quotes below, women are identified by their participant number to retain anonymity. Years since treatment, whether single or double mastectomy (single mx; double mx), and whether they had breast reconstruction are also indicated next to quotes to provide context, although no particular patterns in responses were noted in women who had, or had not, chosen breast reconstruction.

Theme 1: Downplaying aesthetics relative to surviving cancer

A key theme was the priority given to the desire to survive, which dominated women’s experiences at the early stages from diagnosis to mastectomy. This theme was evidenced through statements about survival being more important than appearance. Women wanted to get rid of the cancer and think about aesthetics later. They distanced themselves from the infected part of their breasts which were objectified and seen as separate from their well

body, using objectifying words like “offending article” (P36), “thing” (P4), and “the cancer” (P28). For instance:

The thing for me was just to remove the offending article (P36; 45 years, single mx, not finished active treatment, reconstruction)

It is not clear here exactly whether P36 is referring to the cancerous part of her breast or the whole breast as the “offending article”, but the language used is objectifying and distancing.

I just had a gut feeling that I wanted the whole thing taken rather than a WLE [wide local excision] as the lump wasn’t well-defined. I was concerned at the thought of having to have surgery more than once and thought it might delay the rest of my treatment (P4; 34 years, single mx, less than a year ago, no reconstruction).

In this example, it is clearer that P4 is talking about her whole breast, and again the language used suggests a distancing from the breast that is removed. For the women who completed our online questionnaire, survival was understandably more important than body aesthetics in respect to initial mastectomy, and many women reported that they had not even thought about how they would look after surgery:

I think I just wanted to know it had all gone. I don’t think I really thought about the aesthetics or my body image (P7; 40 years, single mx, less than a year ago, no reconstruction).

Although the majority of women reported that their first priority had been survival, they were also concerned about how they would look afterwards:

At the time my only priority was to remove all traces of the cancer. However, looking back I was concerned with how my body would look and feel following surgery and so

I was glad my surgical team informed me of the possibility of reconstruction (P8, 46 years, single mx, less than a year ago, reconstruction).

Twenty-eight women had looked at post-operative images prior to surgery; sixteen sourcing images online in some form. These data suggest some desire to see what their post-operative bodies might look like, even at the earliest stages.

Theme 2: Body Confidence

This theme focused on body confidence following mastectomy. Although most women reported that initial concerns were very much about survival, and some rejected traditional views on how women's bodies should look, others reported significantly reduced body confidence post mastectomy compared with before:

I have lost all self-confidence in my naked body. I feel fat, bloated, scarred, deformed and unattractive. I have no libido at all (P13, 36 years, single mx, not finished active treatment, unsure about reconstruction).

For women who had only had one breast removed, one of the key sources of dissatisfaction was feeling that their bodies were out of balance. For instance:

I always loved my breasts, now I have one that is really high and small while the remaining one is large and droopy. Understandably hate this (P27, 37 years, single mx, less than a year ago, no reconstruction).

Women reported that lowered body confidence that resulted not from the mastectomy alone but also from the impact of treatment and the knowledge that they may now not be able to have children, had impacted negatively on sexual and intimate relationships:

Self-conscious about and worry about the impact on my intimate relationship with partner a bit, but this is due to a lot of things not just the bilateral mastectomy i.e. weight gain following chemo, menopausal effects of tamoxifen and chemo, knowing that I am probably infertile now etc. (P19, 35 years, double mx, less than a year ago, reconstruction).

Many reported feeling “self-conscious” (P19), with one women reporting that she felt as though others were “always staring” (P23). Other women reported that their confidence in relation to their bodies protected them against some of the more negative impacts. One woman reported that her “embodiment work” had helped her to cope with the changes in her body shape, suggesting a way forward for women who find this more challenging:

I am happy with my body due to all the embodiment work I have done/do for myself. People regularly comment on the fact that they had not noticed even when I am in tight dance kit, that I only have one boob (P50; 53 years, single mx, 1-2 years ago, no reconstruction).

After treatment, some women found sources of strength through rejecting mainstream body shape ideals, and had started to develop new body identities that were different from pre-illness. Some of these women rejected the idea that the look of their body might be important, saying that were not concerned how they looked to others. This served as a source of strength as women renegotiated how they should be treated as women:

Body image has never worried me. I am who I am and I don't go out to impress people (P33, 43 years, single mx, less than a year ago, no reconstruction).

Theme 3: Changed Identity

The third theme focused on identity and body acceptance following mastectomy. For some women, their post-mastectomy body was seen as a giving them a new identity, and they recognised the fact that they would need to habituate to their new, changed bodies:

Since the [mastectomy] I have lost body confidence although it is returning as I get used to the 'new' me. I am happy enough with how I look with clothes on. I'd obviously prefer to be how I was but had no choice but to have surgery so am just accepting of the scars and reconstruction. I have to be to move on and get on with life and not dwell too much (P10; 37 years, double mx, less than a year ago, reconstruction).

Not all women presented this kind of account, and others reported that they still cared about the ways that they looked before their surgery, and that appearance was not less important to them. Some of the respondents also reported that they compensated for the perceived lack of femininity associated with breast removal through wearing clothes that emphasised their legs, and increasing the amount of make-up they wore:

I care less than I did before in some ways, though in others I have become more girly. Wearing skirts more makeup, almost as if I am compensating for the short hair and lack of breast (P4; 36 years, single mx, less than a year ago, no reconstruction).

For some women, getting to recognise and feel comfortable with their post-mastectomy body was challenging, and they felt lost and out of touch with their bodies, with one woman reporting that she had mentally detached herself from her remaining breast:

I feel like I don't recognize myself anymore. I used to wear low cut tops and now I cover up. I have mentally detached myself from my remaining breast as I just want it

gone and any risk of the same happening again (P29; 40 years, single mx, 1-2 years, reconstruction).

The idea of mentally detaching from parts of the body that are seen to be damaged was mentioned under the first theme. Some felt that their bodies had ‘let them down’. However, some were taking active steps to make their bodies stronger:

I want my body to look and feel strong so am doing quite a lot of weight lifting to try and remove the feeling that my body was weak and failed me by getting cancer (P1; 36 years, single mx, not finished active treatment, planning reconstruction).

Theme 4. Treatment Effects

The final theme focused on body-image-related experiences of treatment. Some participants were concerned about showing their scars, and reported that they were “paranoid” (P33) and “hugely unconfident” (P38) in relation to their scars. Others took a pragmatic view, seeing scarring as a necessary result of treatment that had enabled them to survive:

This is a difficult question, because I really do not like my reconstructed breast, particularly the scars that I have from it. However, I know why I have the scars that I do, and the bottom line is that I need them to exist. Of course, I'd much rather have my original breast back, but I don't really think about it that often and when I do, I tend to push the thoughts away and not dwell on it (P40; 38 years, Single mx, 1-2 years, reconstruction).

Others reported that these scars were “war wounds”, enabling them to feel; “proud” of them:

My scars are my war wounds of life. I don't hide away from them. I'm proud of them. Yes my breasts are different and not natural but that doesn't change who I am (P46; 34 years, double mx, less than a year ago, reconstruction).

Although some women saw their scars as relatively positive evidence of a successful battle with cancer, many women were very concerned about weight gain as a result of treatment, and found this more of a concern than breast loss, with eight women reporting that they now “hated” their bodies due to weight gain. Again, this kind of talk around bodies suggests a separation of the ‘real’ self and the hated fat self.

Weight gain due to treatment effects and (in some cases) early menopause was more of a concern than breast removal for many women, supporting Harcourt and Frith (2008) who have also noted that treatment effects may be of serious concern to participants:

Do not feel great about body image at all. Have gained weight due to early menopause, think that bothers me more than my breasts. (P24; 43 years, single mx, 6-10 years, reconstruction).

P24, who had experienced mastectomy at least six years earlier, felt that her weight gain was more of an issue than her breast removal. Concerns about weight gain were also found in women who had had surgery much more recently such as P16:

I am less concerned about my breasts. I am more bothered by my increased weight distribution around my stomach (P16; 37 years, single mx, less than a year, no reconstruction).

Discussion

Survival was initially more important to the younger women who responded to our survey than aesthetics, and at diagnosis women were more concerned about their health than how they looked. Media aimed at women who have experienced breast cancer such as thescarproject.org (which, through photographs, purport to show the absolute reality of breast cancer), tend to focus on women as active ‘survivors’ rather than passive ‘victims’, and draw

into question the relevance of traditional focus on women's breasts as aesthetic or sexual objects, and women's accounts mirrored this kind of view in prioritising survival over appearance. Women also used accounts that distanced themselves from the breast that was removed. Other researchers have noted the tendency for people to distance their primary body, which is seen as well and healthy, from an ill part of the body and have suggested that this fulfils a protective function (e.g. Thomas-MacClean, 2000). The idea of mentally detaching from parts of the body that are seen to be damaged, has also been discussed by other authors writing about experiences of breast cancer (e.g. Holland et al., 2014).

After mastectomy, many women felt that they needed to negotiate a new body identity, to take account of scarring and weight gain resulting from treatment as well as differences in body silhouette and symmetry. Some women felt that they had developed a positive, strong new body identity following surgery. The fact that some of the women who completed our online questionnaire were taking active steps to strengthen their bodies made their stories much more positive than those suggested by other authors such as Manderson (1999). Zebrack (2000) has argued that women may be inspired to create new body identities as a result of cancer, and there was certainly evidence of this in our data. Some women said that their mastectomy scars were like war wounds. In this kind of account, women presented themselves as soldiers who had survived a battle with cancer. This kind of account suggests a good level of control and self-efficacy which have been linked to improved quality of life in women with breast cancer in other work (e.g. Cunningham et al, 1991). The fighting analogy has been well documented, and is often seen in media stories around cancer survival. Interestingly, this promotes a view where cancer is externalised relative to the healthy body, linking with the first theme where women objectified and externalised the cancer.

Although some women used acceptance discourses and talked about renegotiating gender identity, supporting Young (1990), not all women presented this kind of account. For

many of the participants, appearance was as important to them as prior to surgery and some of the respondents reported that they compensated for a perceived reduction in femininity associated with breast removal through wearing clothes that emphasised their legs (also associated with traditional “emphasised femininity”; Connell, 1987). Some found that they struggled with weight gain due to drug treatment, which was more important in relation to body confidence than breast loss. Women were very concerned about not looking slender, in line with qualitative data from other women in the same age range (Grogan et al., 2013), with twelve women reporting that weight gain was their primary concern about treatment. This is important information for those working with young women after and during treatment for breast cancer. Possibly breast removal can be hidden with clothes; however, weight gain and other impacts of treatment such as hair loss resulting from chemotherapy may be much harder to hide, and may be more of a concern to many women than breast loss. Tylka (2011) has shown that body acceptance techniques can be very effective in reducing these kinds of weight concerns in healthy women, and media literacy interventions can be effective in enabling women to critique cultural pressure to be slender (Watson and Vaughan, 2006). There may be a role for these kinds of interventions in the period after women have had mastectomy and are experiencing weight gain as a result of treatment.

Women are often judged on their appearance (e.g. Bordo, 2003), so it is perhaps not surprising that some women felt self-conscious about their bodies after mastectomy. Women also felt that their sexual/intimate relationships had suffered as a result of their mastectomies, supporting Baucom et al. (2006). Breasts have long been linked with traditional conceptions of femininity (Grogan 2008; Lorde, 1980), and are sexualised in popular western media more than other parts of women’s bodies (Haines et al., 2010). Objectification Theory (Fredrickson and Roberts, 1997) focuses on the impact on women of existing in a culture that objectifies women’s bodies suggesting that women learn to objectify their own bodies, and would

suggest that many young women might find it difficult to come to terms with a body that differs from idealised sexualised media images. Fang et al. (2014) have argued that women who are low in objectified body consciousness levels may find breast loss and impacts of treatment easier to cope with, and Kinsaul et al. (2014) have shown that young women who endorse feminist ideologies which critique the necessity for women to look a particular way, have more positive body image, and this was supported in accounts presented here. Further work could investigate the impacts of trying to reduce objectified body consciousness in younger women as part of treatment after mastectomy and follow-up treatment to understand more fully how some women maintain a positive body image following body changes such as breast removal and weight gain whereas others do not, and what can be done to support those who find this more challenging.

Strengths and Limitations

Strengths of this study are the large number of women whose opinions we accessed, and the good degree of information that we had on each woman. Participants were detailed in their responses and shared a lot of information. The relative anonymity of the process enabled this disclosure. There were also limitations inherent in our work. Women were all UK-based, and all who identified their ethnicity were white, so we do not know how far their responses would generalise to other young women who have experienced mastectomy. Further research could examine this through selection of a wider group of women from varied geographical areas and more varied ethnicities. Clearly cultural factors such as degree of sexualisation of breasts and young women's bodies in general, and pressure to conform to an idealised slender but large-breasted figure, may influence how women experience their bodies post-mastectomy, so impacts on body image may vary in women from non-UK cultures. Participants were also part of a supportive young-women-centred network, so may differ from other women in how they view their bodies post-mastectomy.

Key Implications for Health Professionals

1. Although some younger women who have had mastectomies may feel relatively positive about their bodies, some women may “hate” their changed new body and may benefit from additional support in body acceptance. The women who completed our questionnaire were already receiving support from the online support group, so might be expected to have had greater body acceptance than women not receiving this kind of support (Han et al., 2009), though many were struggling with body acceptance. Possibly additional face-to-face support on body appreciation and acceptance might be helpful, along the lines suggested by Tylka (2012). In the UK, Breast Cancer Care (2015) offers women information on local courses on wellbeing and moving forward after breast cancer as well as the support information available on the website.
2. Gaining weight as a result of drug treatment, and early menopause, may be of more concern than breast loss to some young women. Any interventions and post-mastectomy treatment need to ensure that this is discussed in relation to sexual relationships and clothes choices, as well as impacts of breast loss.
3. Younger women may feel happy with their bodies, including their scars. It is important not to assume that they will feel negative, although clearly women in our study may have been receiving more support from their online group than others in the same position so may have been more positive than other women. One of the key findings in this study was the degree of variability in women’s experiences and feelings about their bodies. Listening to women’s individual experiences is crucial in understanding individual concerns and the positives that may balance these.
4. At diagnosis, younger women may feel they have no choice about whether or not to have a mastectomy as they are likely to want to focus on survival. This

needs to be taken into account by consultants in pre-operative discussions, to ensure that women are given all necessary information and sufficient time and space to consider all options carefully, especially the decision about whether to have immediate reconstruction.

Reflexive Analysis

As researchers, we have tried to present women's accounts fairly and disinterestedly although we were moved by these women's stories. The first author is a health psychologist with experience of research on body image, including interviewing women about their breasts, but no direct experience of breast cancer. The second author has a personal diagnosis of breast cancer with mastectomy and reconstruction and is in the same age range as the participants of this study. Her research interests encompass the definition and representations of the female form within, and impacted by, the discipline of fashion and apparel. The analysis we have produced hopefully benefits from having two quite different perspectives on breasts and breast cancer; an insider approach and an approach based on an academic understanding of body image and gender.

Summary

In this study we have been struck by the variability of experience of women experiencing a relatively similar life event. Some women reported developing increased strength and self-efficacy following surgery, and rejected mainstream beauty ideals, reporting that they felt proud of their scars. In general, these young women saw body changes more positively than has been reported in quantitative studies. It is therefore important that health professionals do not expect homogenous patterns of negative responses in women who have had mastectomies, so that they are able to provide tailored support if and when needed.

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