



Women's body image following mastectomy: Snap shots of their daily lives

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1. Background

The impetus for this study stems from the researcher's experience as a registered nurse in an acute surgical setting caring for women following mastectomy. It was noted that concerns around body image seems to permeate women's experience following mastectomy. This prompted a literature review on the topic.

Breast cancer is the second most common cancer in women globally and is one of the leading causes of cancer related mortality in women, with an estimated 1.67 million new cancer cases diagnosed in 2012 (Ferlay et al., 2015). In Ireland, more than 3100 new cases of breast cancer are diagnosed annually (Breast cancer: The facts|Irish Cancer Society, n.d.). On an average during 2011–2012 around 690 deaths were attributed to breast cancer accounting for 17% of all cancer deaths in Irish women (Breast cancer trends report, n.d.). The surgical option of mastectomy in combination with other treatment options, have significantly increased women's survival rates. It is estimated that in Ireland between 2009 and 2013, approximately 32% of women with breast cancer underwent mastectomy within 1 year of their diagnosis (Breast cancer trends report, n.d.).

2. Mastectomy & body image

The literature asserts that mastectomy (removal of one or both breasts), results in surgical scars which can lead to a sense of losing one's femininity, desirability, feeling deformed and low self-esteem in women (Coll-Planas & Visa, 2016; Elmir, Jackson, Beale, & Schmied, 2010; Glaus & Carlson, 2009; Ogden & Lindridge, 2008; Shoma et al., 2009). Women not only experience emotional trauma associated with the diagnosis of cancer but also self-image and physical changes in their body and its functioning after undergoing mastectomy (Freysteinson et al., 2012; Nizamli, Anoosheh, & Mohammadi, 2011). Following surgical treatment, chemotherapy and radiotherapy for breast cancer, women described feeling “Disappointed” on experiencing undesirable changes to their body and felt that their body no longer looked or functioned in the same way as it did before they had cancer (Brunet, Sabiston, & Burke, 2013).

Several studies suggest that body image issues have affected the daily lives of women following mastectomy causing them to feel less

positive and socially isolated with decreased sexual attractiveness and femininity (Andrzejczak, Markocka-Mączka, & Lewandowski, 2013; Arroyo & López, 2011; den Heijer et al., 2012; Maćik, Ziółkowska, & Kowalska, 2012). Some women reported feeling self-conscious about their bodies and their scars after mastectomy and perceived it to impact negatively on their sexual and intimate relationships (Grogan & Mehan, 2017; Jassim & Whitford, 2014).

Women have attributed their decision to undergo a breast reconstruction as a means of returning to being themselves and acquiring a sense of identity or to look their “normal self” (Denford, Harcourt, Rubin, & Pusic, 2011). However, most women experience disturbed body image even after undergoing breast reconstruction (Fallbjörk, Rasmussen, Karlsson, & Salander, 2013; Unukovych et al., 2012). A study on the impact of surgical treatments (breast-conserving surgery [BCS], mastectomy alone, mastectomy with reconstruction) and severity of surgical side-effects on body image of women with early stage breast cancer, reported no significant difference in body image scores of women with BCS and those with mastectomy and reconstruction, over time. Interestingly, one study reported that women who underwent mastectomy alone had higher body image scores at six months than those who underwent mastectomy with reconstruction ($P = 0.011$) (Collins et al., 2011).

Sexuality and relationship with partners are an essential aspect of women's experience following mastectomy. Some women perceived that mastectomy would negatively affect their relationship with their spouses while others perceived that it could have a positive effect on their marriage (Avci, Okanli, Karabulutlu, & Bilgili, 2009). Fear of intimacy in the future is also an issue for women (Loaring, Larkin, Shaw, & Flowers, 2015; Piot-Ziegler, Sassi, Raffoul, & Mastectomy, 2010).

Ceased sexual relationships and absence or reduction in sexual desire was reality for a Moroccan sample of women following their breast cancer diagnosis and treatment (Sbitti et al., 2011). Conversely, after breast conserving surgery women retained some sense of connection to their previous self in terms of body image leading to improved health related quality of life (Hadi, Soltanipour, & Talei, 2012). In some instances, sexual satisfaction and function are more affected than body image following breast cancer treatment (de Moraes, Freitas-Junior, Rahal, & Gonzaga, 2016). However, women have also reported that the support from their husband was incredible highlighting that strong

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family support was “key” to making the treatment more bearable (Williams & Jeanetta, 2015).

In summary, the review highlights that mastectomy has a negative impact on women's body image. Women often feel uncomfortable and perceive that they look different to other women following mastectomy. Notably, these negative perceptions do not change over time. Similarly, following breast reconstructive surgery, some women experience further altered body image which echoes the impact of their breast surgery. Moreover, women perceive that their changed body image impacts negatively on their sexuality and relationship with their partners. However, a dearth of studies in an Irish context was noted.

This study explored women's perceptions of body image following mastectomy for breast cancer, in an Irish setting, in an effort to identify how best to support women in this regard.

3. Methods

3.1. Design

Silverman suggests that a qualitative design is the most appropriate to capture information in relation to social phenomena, exploring people's life histories or day to day behaviour (Silverman, 2005). Descriptive qualitative research aims to encourage participants to describe as precisely as possible what they experience and feel and how they respond (Kvale, 2009). According to Sandelowski “it is a method of choice if the researcher wants a straight description of an event or phenomenon” (p. 339) (Sandelowski, 2000). Hence, to attain more knowledge of women's perceptions of body image after mastectomy, a descriptive qualitative approach was considered suitable.

3.2. Ethical approval, recruitment & participants

Ethical approval was granted from the local Research Ethics Committee. Permission to access the site was obtained from management and key gatekeepers prior to commencing the study.

Participants were accessed through the breast clinic of a large urban university teaching hospital within the Republic of Ireland. Women over eighteen years of age who underwent mastectomy (either unilateral, bilateral with or without breast reconstruction) within the last two years were approached during their follow-up appointment in the breast clinic by the clinical nursing staff who provided them with an enveloped information leaflet, outlining details of the study. A private room was secured to give women an opportunity to read the information leaflet and clarify any issues with the researcher, who was present in the clinic. Women who agreed to participate, indicated that they were happy to meet with the researcher who gave them the option of being interviewed on that day or on an alternative date and time. All women agreed to be interviewed on the day of their follow up appointment, as it was more convenient for them.

Ten women were approached during the months of May and June 2017, and eight women agreed to take part, one of whom participated in a pilot interview. A final sample of seven women was deemed adequate for the study based on the specific information “Information power” of women who met the inclusion criteria (Malterud, Siersma, & Guassora, 2016) and the time available to the researcher to complete the study.

3.3. Data collection

Following receipt of informed consent, data were collected by the researcher using semi structured face to face audio recorded interviews, in a private room, nearby the clinic. This location ensured that the interview was free from distractions, thereby easing the interview process for participants. Having introduced herself to the participant, an icebreaker question or two posed by the researcher, assisted with settling and relaxing the participant. The study details and interview

process were outlined to each participant. When participants were comfortable and ready to proceed, socio-demographic details were recorded. Women were then asked about their perceptions of body image post mastectomy including the impact of body image changes on their daily lives and their relationship with their spouses or partners. In addition, they were questioned about their information and support needs in relation to body image. Probes were used to assist in the interviewing process, as necessary. A leaflet with information on the Irish Cancer Society support services was provided to participants, should they become upset or need further support. Interviews were from between 20 and 45 min duration.

3.4. Data analysis

Data were analysed using qualitative content analysis which involves deriving meaning units from the whole texts (Holloway, Wheeler, & Holloway, 2002). Initially, the interview data were transcribed verbatim and transcripts were checked against each recording and read several times by the researcher to obtain a sense of the whole. Data were then coded and categorised (Graneheim & Lundman, 2004). Coding the interview transcripts involved reviewing the transcripts line by line and paragraph by paragraph, looking for significant statements and coded according to the topics addressed (Graneheim & Lundman, 2004). The researcher compared various codes based on the differences and similarities and organised them into subcategories and categories and finally four themes describing women's perceptions of body image following mastectomy i.e. daily life, body image changes, relationship with spouse/partner and information and support needs, emerged (Fig. 1).

3.5. Rigour

The rigour of qualitative research is determined through the study's confirmability also known as auditability, fittingness, and credibility (Sandelowski, 1986). Credibility and consistency can be established when the analysis of the experiences is acknowledged as being true to the information collected (Sandelowski, 1986). Credibility and consistency were maintained through utilisation of a systematic framework for data analysis (Graneheim & Lundman, 2004). Dependability was ensured by maintaining an audit trail consisting of the literature, memos, notes, verbatim quotes and all material collected during the process of the study to allow for continuous review by an independent researcher. Researcher bias was overcome through the use of

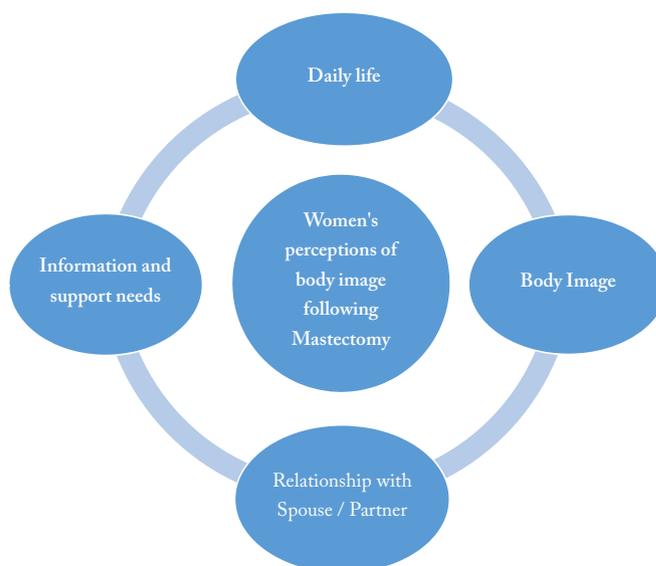


Fig. 1. Women's perceptions of body image following mastectomy.

Table 1
Socio-demographic details ($n = 7$).

Participant	Age(years)	Nationality	Relationship Status	Type of Surgery	Time since surgery
P1	46	English	Married	Left Mastectomy	1 year
P2	61	Irish	Single	Left Mastectomy	2 year
P3	57	Irish	Divorced	Right Mastectomy and expander placement	2 year
P4	51	Irish	Single	Right Mastectomy	1 year
P5	55	Irish	Married	Left Mastectomy	2 year
P6	41	Irish	Divorced	Left Mastectomy	2 year
P7	47	Irish	Single	Left Mastectomy With reconstruction	2 year

bracketing i.e. the process by which the researcher puts aside his/her preconceptions and ideas about the topic under study in order to understand the data as they emerge (Ellis, 2013). The researcher remained conscious of her nursing experience of caring for women being treated for breast cancer. This was facilitated by the researcher recording any preconceptions, and assumptions concerning women's body image following mastectomy, in a reflective diary. A person-centred approach was maintained throughout the interview process. As the interviews progressed, the researcher realized that every woman had a different yet somewhat common experiences to share. Finally, transferability (fittingness) of the findings will be determined by its potential users.

3.6. Findings

Participants were women ($n = 7$) whose mean age was 51.1 years (SD + 6.46, range 41–61 years). The majority of women were Irish, married ($n = 2$), divorced ($n = 2$) or single ($n = 3$). All women were one to two years post mastectomy, one had expander placement ($n = 1$) and another reconstruction (Table 1).

3.7. Daily Life

On asking women about their experience of mastectomy and body image, they mentioned that they were now getting back to their normal lives, as in being “up and about” in a couple of days, and “the surgery did not have much of an impact” on day to day life. One woman described life after surgery as an “acceptance journey”:

“.... Initially I had the poor me, and further down the line, I moved on, and this is how I dealt with it, so it was a learning and acceptance journey” (P3).

Mastectomy was also described as an “inconvenience” affecting women's day-to-day functioning. Being unable to do normal day to day activities surprised some women.

Women referred to the changes they made in clothing as a conscious decision to look normal. In getting back to normal, women described coping with the surgery in different ways. One woman related how she used humour (P2), while another mentioned choosing a healthy lifestyle (P6).

Societal views impacted on women's perceptions of body image following mastectomy as evident in:

“society has a lot of influence in the way we think in relation to body image” (P7).

One woman mentioned wearing prosthesis for the benefit of others as opposed to her own benefit:

“I wear it at school because of work, I am nearly doing it to comfort other people than to comfort to myself” (P6).

Another woman's decision to have reconstruction surgery was influenced by her daughter's encouragement. This woman decided to “opt for the surgery” as she thought her daughter was “right” (P3).

Treatment with Tamoxifen and its side effects were a source of upset for one woman as “people” mistook the bloating caused by her

treatment for pregnancy.

Regarding reconstruction, one woman verbalised how her decision not to have reconstruction evoked questions from people around her:

“Generally, people are shocked when you tell them you have chosen not to reconstruct and have chosen to remain flat,why would you want a bag of silicone which isn't you, strapped to you, some people want that, because society says you know” (P1).

Therefore, getting back to normal and coping with the mastectomy posed a challenge for women. Oftentimes, the views of others impacted on women's decisions and took precedence over women's own needs and desires.

3.8. Body image

On asking women about changes in their body image following mastectomy, while women were positive most of the time, they were also worried about their day to day appearance. At times, certain situations made them feel less confident and evoked a disturbed body image as apparent in:

“On a personal level, one part of my brain says, “you are lucky to be alive” “live with it” get over it and move on.... and the second part is I have given up on my sexual confidence and body and the positive way I felt about my body.” (P3).

Women experienced difficulty on viewing the surgical site for the first time as they were reminded of the fact that their breast was no longer there. Many women mentioned that when they looked in the mirror, they felt bad, but their way of coping was either to avoid looking in the mirror or just say “get on with it” (P1, P3). Women described looking at themselves as “disturbing” (P4) “upsetting” (P3), “altered shape” (P2), “different” (P6) and “conscious” (P5). But most concluded that an important part of their body was missing.

Trying to be positive however remained juxtaposed to an underlying sadness and upset that things had changed. One woman mentioned being positive about her body yet being self-conscious and not wanting her husband to see her following mastectomy (P5).

Avoidance and fear of looking at the surgical site were also apparent:

“Even if I was home now, in the morning I want to be dressed very quickly, I don't want to hang around, So, I don't have one boob hanging” (P2).

Despite expressing sadness on losing her breast, one woman agreed that “body positivity” exists “out there”:

“When I look at it in the shower it would make me sad looking at my breasts. I think it's great that there is body positivity out there now, and it's not all in one size, it's great to see the variety these days, it's just goes to show how important body image is to women” (P6).

From these statements, it is evident that body image changes due to breast loss caused underlying sadness and upset for women. Women had mixed feelings ranging from being positive to being afraid, upset, embarrassed and sad. Conversely, women coped by avoiding these

bodily changes and “getting on with it.”

3.9. Relationship with spouse/partner

As already alluded to regarding perceptions of body image, women spoke of being embarrassed and anxious about their relationship, since they now had only one breast. Mastectomy was perceived by some to have a negative effect on their relationship with their partner:

“I would be quite embarrassed, I think. I would be less confident obviously. Confidence does go down” (P2).

In contrast, one woman highlighted that her partner's positive views and support made it easier for her following surgery:

“My husband said very early on, it doesn't bother me what you look like as long as you are here, and I took him at face value, and that has been the case, so that made it much easier” (P1).

Women expressed being happy with the support from their partners. However, they were also anxious about how their partner felt about their body changes after mastectomy which prompted one woman to cover up the surgical site during intimacy:

“After surgery when I was feeling a bit better we met up and we did have sex, and I kept my top on always, all the way through but afterwards I kind of wanted to know how he felt about it... he said he didn't even notice, I suppose he is being nice and trying to be supportive as well” (P6).

Regarding reconstruction, women's views varied. One woman who had reconstruction, perceived it as making a huge difference. However, most women did not want reconstructive surgery. Two women who considered reconstruction, were anxious about whether it would be beneficial, or whether it was going to be a “dragging process of waiting for the surgery” (P6) and have no benefits at all. This woman, who was unsure initially began to view reconstruction as a means to feeling attractive stating:

“I don't want to go around the place like Marlin Monroe either, But, I want to feel attractive and we all like to look our best when we go out. So, I think that's what made me change my mind in the end” (P6).

Reconstruction was perceived as looking “reasonably normal” (P7). On the contrary, one woman stated with certainty that she did not want reconstruction:

“I knew that I didn't want reconstruction, before I went in, I didn't feel that I wanted something that wasn't me on my body or in my body, take the cancer out, take the breast away, and that's fine” (P1).

Another mentioned that the only reason she would consider reconstruction would be for her love life and for her husband/partner.

In summary, decreased confidence regarding sexuality and initiating a new relationship were apparent for women post mastectomy. Reconstruction was viewed positively by some and less so by others. Overall, women seemed happy when their partner was supportive. Embarrassment and lack of confidence caused some women to hide the mastectomy site by wearing clothing during sexual relationships.

3.10. Information and support needs

Women were grateful for the excellent support from family, health care professionals and hospital staff from the time of diagnosis to treatment. However, some women said that they would have benefitted from more information.

The need for partners to be supported and to be actively involved in education related to surgery, was highlighted:

“I think they could do with a support group for all of them, they could be told what to expect or what it might look like, maybe some pictures to say

this is what it's going to look like. To let them know, don't be shocked and be supportive. Your partner may not want to have sex for a while and may not feel like a sexual being, she might want to keep her top on for the next year” (P6).

The positive impact of media for advertising for breast cancer was highlighted by one lady who was prompted to seek medical help after seeing an advertisement on both radio and television:

“Advertising is key to taking immediate action. “Information is key,” (P5).

Most participants were quite happy with the Irish health services and praised the health care professionals who looked after them on their journey. They also acknowledged the excellent support they received, and how it helped them to cope during their post-operative period. Women acknowledged the supportive role of the nursing staff throughout the recovery phase and described the process as a positive journey. One lady who is now two-year following mastectomy voiced:

“I have no stage in my journey, which was ever staggered, and I got the best surgeon and I got a wonderful nurse, it was all positive. I had enough of all the information and support, that I didn't need to go to any support services. So really it was a positive journey for me” (P3).

and, one woman concluded saying:

“I am so grateful for everything here, great clinic, and I know people are mad busy, but people are always spot on” (P5).

4. Discussion

In exploring women's perceptions of body image post mastectomy, none of the emergent themes are mutually exclusive, as women's thoughts intertwine to describe their daily lives, at that time.

Similar to a recent UK study (Grogan & Mehan, 2017) in the current study, variations in women's experiences of daily life following mastectomy were apparent. Perceiving reconstruction as a means to having a good “love life” and to looking “normal” was reiterated in a previous study which highlighted that while some women wanted to look or feel normal, according to their own personal standards of normality, others were seeking to look normal in accordance with societal standards, following mastectomy (Denford et al., 2011). In the current study, women who wanted to look “normal”, opted for an implant or a reconstruction.

Women's experience of diagnosis and treatment as being an “acceptance journey” and being “grateful for life”, echo the narratives in a previous Australian study. It was emphasised that despite all the physical and emotional turmoil experienced, breast cancer and surgery had made women stronger individuals and this strength came from within themselves (Elmir et al., 2010).

Similar to a previous Canadian study of women following mastectomy (Freysteinson et al., 2012), at times women in the current study were in denial and they tried to escape from reality by hiding the scar and wearing loose clothing. The ongoing challenge of seeing their mastectomy scars for the first time (Davies et al., 2017) was also a reality for women in the current study. As in previous studies (Brunet et al., 2013; Davies et al., 2017; Jassim & Whitford, 2014), some of the women in the current study avoided looking at themselves in the mirror, clearly indicating a decreased body image.

Despite reduced self-image, women's perception of self was often linked to other's perceptions. Some women in the current study perceived that other people had a bigger problem with their mastectomy than they had themselves, and this made them feel uncomfortable. These findings are consistent with a study where women described grieving their breast loss and being worried about how they might be perceived in society (Nizamli et al., 2011). Similarly, women have perceived mastectomy to be an attack on their body image and viewed

themselves as being an “odd-ball”, which caused social isolation (Arroyo & López, 2011). Interestingly, women in our study changed their dress style in order to be accepted in society as well as to please their partners.

A previous study (Freysteinson et al., 2012) reported that women experienced undesirable changes to their body that were both visible and invisible to others, which is consistent with the findings of this study where one woman described how people misinterpreted the bloating side effect of Tamoxifen as being due to pregnancy. In addition, women perceived that their bodies no longer looked or functioned in the same way as it did before their cancer diagnosis and treatment. Similarly, women have reported persistent worry “about no longer being desirable” due to the effects of chemotherapy and the scars of mastectomy (Coll-Planas & Visa, 2016). Overall, it is evident that women are conscious of their changed appearance post mastectomy and worry about how others perceive these changes.

Consistent with previous studies, women's perceptions of self, influenced their relationship with their spouse/partner and their decisions around sexual relationships. Some women often tried to hide their mastectomy site from their spouse/partners, due to their changed body image. This is consistent with previous studies where following mastectomy, women revealed that they began to cover up their body during intimate relations (Andrzejczak et al., 2013) and others voiced that mastectomy could negatively affect their marital relationships (Avci et al., 2009).

As in the current study, sexual satisfaction and functioning have been found to be more affected than body image, for some women following mastectomy (de Morais et al., 2016; Piot-Ziegler et al., 2010). In addition, two studies (Loaring et al., 2015; Sbitti et al., 2011) reported that some women experienced a decline in sexual relation with partners and felt reduced sexual confidence which was consistent with the current study. Therefore, in addition to reduced femininity, decreased sexual confidence also impacts on women's sexual functioning following mastectomy.

While women voiced that their spouse/partner was supportive, they worried about how they might view their body, following mastectomy. One woman was worried about how her partner would perceive her while having sex, another considered reconstruction as a means to having a normal sex life. This echoes findings from a previous study where women experienced long-term sexual problems following breast cancer diagnosis and treatment and engaged in sexual activity depending on the “demand from their husband” (Wang et al., 2013).

A substantial proportion of women consider their spouses' opinion when making treatment decisions (Hawley et al., 2009). A statement from one participant in the current study clarified that her decision not to undergo a reconstruction was based on the fact that her spouse did not want her to have reconstructive surgery. Another participant's decision to proceed with a reconstruction was to maintain a normal sexual life with her partner. Conversely, one woman mentioned that her partner's support was everything for her, thus she didn't even consider reconstruction. This is consistent with a previous study which highlighted that the partner's acceptance of a changed appearance in the woman's body and his reassurance of her desirability helped to maintain her sense of attractiveness (den Heijer et al., 2012).

Breast conserving surgery has been found to have a better impact on women's quality of life (Hadi et al., 2012). Although all women had mastectomy, only one woman in the current study perceived breast reconstruction as the best way to being herself and this reduced her anxiety around being in a relationship. Most women did not want reconstruction because they preferred not to have something “artificial” and “not part of themselves”, within their body.

It is clear from the study findings that women were apprehensive about approaching their spouse/partner following mastectomy and were worried about their response. Therefore, perceptions of both women and their spouse/partner have potential to affect sexual relationships following mastectomy.

Overall, women were complementary about the support they received from health care professionals (HCPs), which helped them to remain strong and positive. Similarly, another study highlighted that support and liaising with doctors and nurses were valuable resources that helped women towards a speedy recovery (Elmir et al., 2010). However, in the current study some women felt that their partners could benefit from education in relation to mastectomy.

Additionally, two participants said they would have benefitted from more education in relation to their surgical site and its appearance after surgery, emphasising that this might have reduced their anxiety in dealing with the scar.

5. Limitations

There are some limitations to this study. Firstly, women were interviewed at least one-year post mastectomy. Therefore, their perceptions of their body image are likely to have changed over time and may not be reflective of their feelings in the immediate post mastectomy period. Secondly, while women who were currently undergoing chemotherapy and/or radiation were excluded from the study, previous treatment with adjuvant therapies was not assessed, unless women volunteered the information. Finally, neither did the study assess the influence of various psychosocial characteristics such as age, cultural background, marital status on perceptions of body image as this was not the purpose of the study. These have implications for further studies.

6. Implications for practice

Findings revealed that both women and their significant other would have liked more information on the appearance of the scar post mastectomy. This has implications for HCPs to provide further information to women who opt for mastectomy, in relation to the surgical scar. The need for support for both women and their spouses/partner is apparent. Continued awareness about breast cancer through media and advertising, encouraging women to consult promptly with an HCP, following discovery of a breast symptom, is essential.

7. Conclusion

This study adds to the body of knowledge on women's experiences in relation to body image following mastectomy in an Irish setting. It provides a glimpse of the day-to-day issues highlighted by women as they struggle to regain their normal lives within a different body image. Findings highlight how body image changes have affected women's daily lives, perceptions of their body image, relationship with their spouse/partner and their information and support needs. Women's struggle to remain positive while coping with a major body image adjustment is palpable. Perceptions of others including family, spouse/partner and society in general are ever-present. The need for continuing support and education for women diagnosed with breast cancer and their spouses/partners, is apparent. The role played by the media and social media in encouraging women to seek help promptly, is emphasised. The study reminds us that despite advances in treatments and supports available to women diagnosed with breast cancer, the emotional distress of coping with body image disturbance, can never be under estimated.

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