

2018-05

'It's a silver lining': A template analysis of satisfaction and quality of life following postmastectomy breast reconstruction

Matthews, Hannah

<http://hdl.handle.net/10026.1/16318>

10.1111/bjhp.12299

British Journal of Health Psychology

Wiley

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

Abstract

Objective: In the United Kingdom, the number of women undergoing post-mastectomy breast reconstruction is increasing. Consequently, exploring patient-reported outcomes in breast surgery has become increasingly important. This study investigates satisfaction and quality of life following post-mastectomy breast reconstruction.

Design: Qualitative research design.

Methods: In-depth, semi-structured telephone interviews were conducted with 25 women, (Age, $M = 53.08$, $SD = 8.41$) following breast reconstruction in the United Kingdom. Data were analysed using template analysis which produced three first-level, 13 second-level and 19 third-level themes.

Results: Following reconstruction women reported improved emotional functioning, although this was often accompanied with deterioration in physical, sexual and/or social functioning. Women positively appraised their breast appearance, although some reported a decline in satisfaction over time, attributing this decline to their chosen reconstructive technique. Many women accepted the inevitability of scarring and most perceived their scars as a representation of their journey, signifying survival. Generally women were satisfied with the outcome of their reconstruction, although on reflection some would not have opted for reconstruction. Following breast reconstruction women were increasingly likely to experience the fear of recurrence, attributed to no longer being able to have a mammogram on the affected breast(s).

Conclusions: This study provides new insights into post-mastectomy breast reconstruction and is a novel application of template analysis. The analysis demonstrates only slight variation in some categories of experience among women, despite a heterogeneous sample. The findings allow researchers and clinicians to focus on specific dimensions of satisfaction and quality of life to support the needs of women following reconstruction.

Background

For many women reconstructive surgery provides the opportunity to restore the appearance of the breast(s) and reduce the psychological effect of mastectomy (Denford, Harcourt, Rubin & Pusic, 2011). However, the decision to undergo reconstructive surgery is complex, as the patient, in consultation with the surgeon, must decide between the different methods of reconstruction (autologous or implant or a combination of both) and the timing of reconstruction (immediate or delayed) (Sheehan, Sherman, Lam & Boyages, 2007). Implant reconstruction involves the use of prosthetic implants composed of a silicone elastomer envelope filled with either silicone-gel or saline (Bar-Meir, Eherenfeld & Shoenfeld, 2003). Reconstruction can also be achieved with the use of tissue expanders and implants. A tissue expander uses an inflatable breast implant to stretch the skin and muscle to later allow for a permanent implant (The National Mastectomy and Breast Reconstruction Audit, 2011). Autologous breast reconstruction uses the patient's own tissue in two ways: either a pedicle or free flap reconstruction. Pedicle flap reconstruction involves rotating a flap, comprised of skin, fat and usually muscle whilst keeping intact a tube of tissue containing its blood supply (The National Mastectomy and Breast Reconstruction Audit, 2011). Free flap reconstruction involves a flap being completely detached from the body along with its supplying blood vessels, the flap is then placed at the mastectomy site and the blood supply restored by the joining of the vessels that supply the flap to vessels in the breast area (The National Mastectomy and Breast Reconstruction Audit, 2011). The most common autologous reconstructive techniques use tissue from the upper back (latissimus dorsi flap, LD) or abdomen muscle (transverse rectus abdominis myocutaneous flap, TRAM and deep inferior epigastric artery perforator, DIEP).

It is highly debated which type of reconstructive technique is the most appropriate within the field of plastic and reconstructive surgery (Dutra et al., 2012). This is problematic as patients are often presented with more than one viable surgical option. Nevertheless, some previous literature indicates higher satisfaction rates with autologous tissue based procedures than implant-based reconstructions (Atisha et al., 2008; Yueh et al., 2010). Moreover, we have previously reported DIEP patients experience greater breast and outcome satisfaction compared with other types of reconstruction (Matthews et al., 2017). Furthermore, patients must also decide the timing of breast reconstruction. Reconstruction could be either during the same procedure as mastectomy (immediate) or at a later stage (delayed). Advantages of immediate reconstruction include a superior aesthetic result (Al-Ghazal, Sully, Fallowfield & Blamey, 2000), a lower number of surgical procedures, hospitalisations and recovery periods (Barry et al., 2014). Immediate reconstruction is also significantly more cost-effective than delayed reconstruction on a direct resource-cost basis (Yang, Zhu & Yan, 2015). However, delayed reconstruction allows the patient more time to consider their reconstructive options and for the completion of cancer treatment (Shakespeare & Hobby, 2001).

In the United Kingdom, the rate of breast reconstruction is increasing (National Mastectomy and Breast Reconstruction Audit, 2011). For many women breast reconstruction is associated with positive effects on breast satisfaction (Oiz, 2005), body image, self-esteem (Ballard et al. 2015), sexuality (Filiberti et al., 1989), psychological wellbeing (Howard-McNatt, 2013),

and quality of life (National Mastectomy and Breast Reconstruction Audit 2011: Matthews et al., 2017). These benefits have been observed for both immediate and delayed reconstruction (Nissen et al., 2001), and across a number of procedures (Atisha et al., 2008). However, despite the assumed psychological benefits, across all epidemiological studies uptake of breast reconstruction is less than 50% (Alderman, McMahon & Wilkins, 2003). Moreover, a systematic review found patient-reported outcomes of breast reconstruction after mastectomy are similar to outcomes of mastectomy alone (Lee, Sunu & Pignone, 2009). The review also included four high-quality studies which reported poorer quality of life, body image, or sexual outcomes in women who opted for mastectomy with reconstruction compared against mastectomy alone (Arora et al., 2001; Janz et al., 2005; Nissen et al., 2001; Rowland et al., 2000). Therefore, with some mixed findings reported in the literature understanding the wide-reaching effects of breast reconstruction has become increasingly important for both research and clinical practice.

Post-operative satisfaction and quality of life are often deemed the most important measures of surgical success (Ceraadini & Levine 2008), although these measures are often conceptually confused, with relatively few studies distinguishing between types of satisfaction, specifically breast satisfaction (e.g., size, shape and symmetry) and outcome satisfaction (e.g., overall evaluation of surgery, expectations and decision regret). For example, one study reported 93% of women were satisfied with their breast reconstruction, although the reasons for their satisfaction were not explored (Noone, Frazier, Hayward and Skiles, 1982). However, the National Mastectomy and Breast Reconstruction Audit (2011) utilising the Breast Q measure (Pusic et al, 2009), demonstrated positive effects on both outcome satisfaction, breast satisfaction and quality of life following breast reconstruction. The development of the patient-reported outcome measure, The Breast Q (Pusic et al, 2009) and the conceptual model of satisfaction and quality of life in breast surgery patients (Klassen et al. 2009), allows researchers and clinicians to facilitate the distinction of breast satisfaction, outcome satisfaction and quality of life. Previously, we examined satisfaction and quality of life following breast reconstruction with a quantitative structured questionnaire-based research design, and in this study a number of participants reported a struggle to quantify their experience numerically (Matthews et al. 2017). Consequently, the present study uses a qualitative approach to explore women's experiences of breast reconstruction in relation to satisfaction and quality of life in order to improve our understanding of post-mastectomy reconstruction. Qualitative analysis of breast reconstruction specifically exploring patient satisfaction and quality of life is limited, yet qualitative methods are particularly suitable for looking at patients' experiences' and perceived outcomes of plastic surgery (Shauver & Chung, 2010), and may allow for elaboration, nuance and a further depth to understanding.

Methods

Participants

Eligible participants were post-mastectomy breast reconstruction patients, aged 18 or over and English speaking. Women were excluded if they were undergoing active treatment or palliative care for breast cancer. Sociodemographic and clinical information of participants is

displayed in Table 1. Representatives from UK-based cancer organisations promoted and distributed postal or email information to potential participants. Word of mouth/ snowball sampling was also adopted to maximise recruitment. The recruitment strategy is illustrated in Figure 1. Relative variation was achieved within the sample (e.g., age, type of reconstruction, time since surgery and marital status) and facilitated the production of a more encompassing understanding of reconstruction than would be possible with a homogenous sample. Enrolment in the study continued until the point of data saturation, obtained after interviews with 25 participants. The mean age of women was 53.08 ($SD=8.41$), with 64% of women electing for immediate reconstruction and 36% delayed between 2001 and 2016.

Data collection

Following university ethical approval (P46098), a semi-structured interview schedule was developed through a review of relevant literature and discussion with two consultant plastic surgeons involved in breast reconstruction surgery. The interview schedule is displayed in Table 2. Additionally, some questions were adapted from interview items used by Klassen and colleagues (2009) in order to explore both predetermined and emergent issues relevant to the research question. Data were collected by telephone through semi-structured, digitally recorded interviews conducted by H.M between November 2016 and May 2017. H.M is an experienced qualitative researcher who had established a professional relationship with participants through the recruitment and interview process. The interview schedule was piloted for the first three interviews. This allowed the interview schedule to be reviewed in order to identify areas where more details were required and to modify or remove items that were deemed ineffective or did not ‘fit’ against the research questions. Interview length ranged from 30-80 minutes. Interviews were transcribed in verbatim and used an abbreviated form of the Jefferson system of notation (Jefferson, 2004). Data were organised for analysis using Nvivo 11 (QSR International Pty Ltd, 2015).

Data analysis

The data were analysed using Template Analysis (TA), which involves the development and subsequent refinement of a coding template to represent the themes identified in the data (King, 1998). TA was selected as an appropriate data analysis method as it affords a clear, systematic yet flexible approach to data analysis (Brooks, McCluskey, Turley & King, 2015). Within the template, codes are ordered hierarchically with the highest-level codes representing broad themes in the data, and the lower level codes demonstrating more narrowly focused constituent themes. Following standard TA methodology, three *a priori* codes were identified based on the BREAST-Q[®] reconstruction measure (quality of life, breast satisfaction and outcome satisfaction) (Klassen et al., 2009). *A priori* codes were used as a provisional framework for the coding template, although were open to modification throughout the analysis.

H.M conducted the initial analysis through successive readings of four transcripts and identified initial codes, guided by the *a priori* codes. Analysis continued by H.M, A.T, I.W and W.C. with the coding of transcripts in sets of three for the development and refinement of

the subsequent templates. Refinements of the templates included inserting themes, deleting themes and changing the scope/title of themes. Template 8 was considered the final template, as all sections of data were of clear relevance to the research question and the template was deemed well defined by all team members. The final template is displayed in Figure 2.

Rigour of Analyses

Quality assurance of TA was established following the methods recommended by King (2012). At each stage of the analysis each template was subjected to independent scrutiny with the authors of this study and a subject expert coded a subset of transcripts to highlight the similarities and differences within the analyses, which were discussed until a consensus was reached. An audit trail was also maintained demonstrating all stages of the analysis from the raw transcripts to the final interpretation of the data. This study also adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007).

Results

Three first-level, 13 second-level and 19 third-level themes were identified. Figure 2 depicts the final coding template. Below, first level themes are described and all lower level themes are illustrated with a series of extracts indicative of interview data.

Quality of life

Quality of life explored women's emotional, physical, sexual and social experiences prior to and following reconstruction. Quality of life was discussed during the preoperative perioperative and postoperative phases and these time periods became the temporal anchor around which the narratives were discussed.

Often, women who elected for delayed reconstruction reported grieving the loss of their original breast(s). This grieving process affected women at different temporal points. Some women mourned for their loss prior to reconstruction, whilst others described experiencing a sense of grief months or even years later.

I was going through a grieving process, it was great to know I would wake up cancer free, but there is a lot of your femininity and whole psyche tied up with it (P21, 38, immediate bilateral implant).

Most women (particularly those who were satisfied with their reconstruction) suggested the procedure allowed them to establish a new normality.

I think having the reconstruction was a way of not thinking about breast cancer every day or every time I get undressed (P4, 67, immediate unilateral LD and implant).

Many women described the debilitating nature of reconstruction. There is tentative evidence of a link between the type of procedure and satisfaction, with women who opted for autologous-based reconstructions reporting greater physical burden than those who opted for implant-based reconstruction.

I'm really pleased with the appearance of my breast but it has debilitated me, because I'm not mobile but it is just one of those things (P15, 60, delayed unilateral LD and implant).

Fourteen women described experiencing breast and/or donor site pain and five women described relentless pain which occasioned physical and psychological strain. Breast pain was particularly prevalent with women who opted for implant reconstruction.

The only thing that bothers me is the constant pain of the implants, where I had my radiotherapy I grew fibrosis everywhere so the implants are hard like a piece of wood on both sides (P7, 50, immediate bilateral implant).

Other women reported unusual and unfamiliar breast sensations following reconstruction. Often this led to women feeling disconnected from their reconstructed breasts and denouncing ownership, demonstrated by phrases such as "*it's not really me*" (P7) and "*they're not boobs*" (P22).

My husband gets a bit freaked out, he feels that the TRAM flap one feels a lot smoother inside, and the other one (unaffected breast) is a bit lumpy and feels a bit strange. I do not like him playing with them because in my head I know they're not boobs so do not play with them as if they are, being my attitude. I just hang clothes off them because they're not boobs (P22, 37, delayed unilateral TRAM, LD and DIEP).

Consequently, the participant no longer constituted the caressing of their breasts as means of sexual arousal. This theme was particularly apparent with women who opted for implant-based reconstruction, with some women describing the synthetic nature of their breasts.

All women who opted for autologous-based reconstruction described discomfort at the donor site, with the level of discomfort ranging from slight to severe, and intermittent to constant.

I definitely feel my whole body has changed my tummy button is much higher, so my waist is in a different place and so my hips kind of feel bigger, and all my trousers kind of fit differently and that took quite a lot of getting used to. It is a bit odd really having a healthy area damaged and taking a long time to recover (P6, 48, immediate unilateral DIEP).

Women who opted for delayed reconstruction described a number of prosthesis mishaps, the inconvenience of a prosthesis and the distress associated with wearing a prosthesis. Women described their prostheses as "*uncomfortable*" and "*impractical*" which for some caused anxiety and embarrassment. As a consequence, wearing a prosthesis often results in a substantial burden and a reduction in quality of life.

It [the reconstruction] has made a massive difference, as I am quite active and I can just get up and go now. Whereas, before I would drop the bloody thing and felt like throwing it out the window (P14, 50, delayed unilateral LD and implant).

Nearly all women reported a decline in the frequency and satisfaction of sexual intercourse following reconstruction. Women attributed this decline to pain during intercourse, reduced breast sensitivity, treatment-induced menopause and appearance related concerns.

It has gone [my sex drive] because I remember how I felt before and now it is mental when you have sex. I feel like I need to think about something harder, and it [sex] is less physical. You really have to try not to think this is hurting and then there is no sensitivity in the breasts and the menopause as well (P7, 50, immediate bilateral implant).

However, many women felt their feelings of sexual attractiveness returned to their normal levels following reconstruction and some participants even stated they felt their sexual attractiveness increased. However, almost all women had not returned to their previous level sexual functioning, and some women attributed this to their spouse's reaction towards reconstruction.

I still feel sexually attractive and strangely, many people have complimented me saying, I look far better now than I did a year ago, I think it is probably a bit more of a zest for life. I am quite happy to have it [sex] and body confident but it is my husband who is not, he is either not body confident or not confident to look at my body (P16, 51, immediate unilateral TRAM).

Nearly all women reported loss of breast sensitivity following reconstruction. Whilst, some women described a sense of sadness towards this loss, others embraced the loss of sensitivity and rationalised this as ultimately minimising the pain of further surgical procedures, particularly nipple-areolar complex tattooing.

No, which is a shame [loss of breast sensitivity] but I would rather not have to worry about still having breast tissue. I mean I still have what 5% of my original breast tissue, but that is tiny compared to what I had and it is a small price to pay (P21, 38, immediate bilateral implant).

Some women stated following reconstruction they were able to return to normal levels of social functioning, however others reported a sustained decrease in social functioning.

Sometimes I feel like a bit remote from things and I do feel differently. I have always loved small talk, and I loved going into crowded rooms and chatting to everyone but I do not feel like doing that now (P23, 56, immediate unilateral implant).

Some women reported feelings of physical vulnerability following reconstruction and the need to protect their bodies in a social setting. This physical vulnerability contributed to psychological problems including anxiety, which sometimes forced women to withdraw from social situations.

I wouldn't say it's an embarrassment but I'm just conscious of needing to be careful, and if I'm in a crowd I don't want to be jostled. I almost feel like I need a bit of a shell around myself (P6, 48, immediate unilateral DIEP).

Other women in social situations concealed their reconstructions, as they feared others might perceive them as narcissistic or superficial for having a reconstructive procedure closely associated with a routine cosmetic augmentation.

I am conscious of that and if I am going out trying to find the right clothes to wear, that do not make it obvious so that people do not know, so it does knock your confidence, definitely (P11, 48, immediate unilateral implant).

Breast satisfaction

Breast satisfaction explored perceived body image in terms of satisfaction with breast appearance, appearance expectations and postoperative issues including scarring and nipple reconstruction. Most women were satisfied with the appearance of their breasts following reconstruction. Often, women who breastfed their children described feeling more satisfied with their breasts than prior to mastectomy.

To be honest I have had two kids and I breast-fed them both so I have a new lease of life up top (*laughs*). It is looking great and I am looking 20 years younger, so not only am I not without they are better than they were (P9, 47, delayed unilateral DIEP).

However, three women were distressed at the appearance of their breasts and described unresolved physical and emotional problems in relation to the appearance of their breasts following reconstruction. Yet, all women were able to take some satisfaction in that their reconstruction had provided them with a replacement breast.

I am in limbo now [waiting for further reconstructive procedures] but I am happier that I do not have a prosthesis. I am actually more unbalanced [at the chest site] so for me that is a negative, although I am grateful for what they have been able to achieve and this is where I struggle now (P13, 51, delayed unilateral DIEP)

Over time, some women reported improved satisfaction following a series of operational procedures such as scar revision, lipofilling, and nipple reconstruction, although other women reported a decrease in satisfaction over time due to either the ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords.

When it was all first done yes it was fantastic, scars aside the upright and the perkiness but because the DIEP flap is a natural thing they do droop naturally. Ok we are a couple of years on and they are starting to sag a little bit, and the one on the left that had the lift has started to droop too and I didn't realise that would happen so quickly, but it doesn't matter I mean honestly it doesn't matter (P9, 47, delayed unilateral DIEP).

In relation to expectations of their breast appearance some women suggested their breast appearance met or even exceeded their expectations.

It absolutely amazes me and it completely exceeded my expectations. I never believed I would be able to wear a swimming costume and no one would tell it is not my real breast (P6, 48, immediate unilateral DIEP).

However, a few women described feeling disappointed with their breast appearance, which may have resulted from a mismatch of expectations and outcomes. Many women discussed the inevitability of scarring due to the substantial surgery required. Through this awareness, most women were able to accept their scars as part of the reconstruction process.

I just thought that there has to be a scar somewhere for the operation and because it looks so good [the reconstructed breast] the scarring has never bothered me (P8, 49, immediate unilateral implant).

Nearly all women perceived their scars in a positive manner with many women describing their scarring as “*lovely*”, “*wonderful*”, “*amazing*”, “*brilliant*” and “*stunning*”. This would suggest generally women are proud of their scars as they represent their breast reconstruction journey and signify survival and resilience.

They are what they call the war wounds and I am quite proud of them really (P17, 62, delayed unilateral DIEP and LD).

However, three women perceived either their donor or breast scarring in a negative manner. These women struggled to accept their scars and subsequently their breast into their newly formed body image. Three women also described their spouse’s distress towards the appearance of their scars which negatively affected their own acceptance.

I try not to look at them really and my husband never sees me naked on the top anymore. I cannot and he cannot hide it because it is too painful to look at it (P7, 50, immediate bilateral implant).

Thirteen of twenty-five women opted for nipple-areolar complex reconstruction. For some women nipple reconstruction represented the final chapter of their journey and provided a more accurate representation of the natural breast.

I had the nipple put back on and that is like the cherry on top (P17, 62, delayed unilateral DIEP and LD).

However, most women reported a decline in satisfaction with nipple-areolar complex reconstruction over time. Many women attributed this to the fading of the nipple-areolar complex tattoos, although most women were not concerned and only a few sought revisions.

The nipple tattoo fades unfortunately but the only other option was to have a permanent tattoo from a tattooist, but I am not going to bother with all that (P2, 72, delayed unilateral LD)

Outcome satisfaction

The theme *outcome satisfaction* captured women's overall appraisal of satisfaction with their breast reconstruction. This encompasses whether their expectations were met, the impact surgery had upon their lives and satisfaction with the decision to reconstruct the breast. Many women described experiencing a mixture of expectations and emotions towards reconstruction.

I do not think anyone would have it done if they knew what they were going to go through, although there are pros and cons for everything and I am glad now that I had it done (P15, 60, delayed unilateral LD and implant).

A number of women suggested if they were aware of the full extent of the procedure they would have not opted for surgical reconstruction. However, after the successful completion of the reconstruction process nearly all women were satisfied with the appearance of their breast. Subsequently, most women were content with the decision to reconstruct. Several women described underestimating the extent and complexity of breast reconstruction surgery, despite this often being emphasised by their oncologists and plastic surgeons.

Absolutely traumatised [initially following reconstruction] and its different when you're ill because you are having a mastectomy and treatment to save your life, but choosing to have cosmetic surgery to improve how you feel is different. I must say I did not know just how large of an operation it was (P3, 54, delayed bilateral TRAM).

Most women had realistic expectations of recovery periods and understood the physical and psychological burden of reconstruction.

I made a very good recovery far better than I was expecting, both mentally and physically from the reconstruction (P1, 52, immediate unilateral DIEP).

Many women described the positive impact of breast reconstruction, with some women describing reconstruction restoring and enhancing body confidence and overall confidence. As reconstruction allowed these women to overcome the role of a cancer patient and adjust to their new identity following breast reconstruction.

I really feel body confidence and strangely more so since the operation. I feel like I have had cancer come through it and WOW so I just feel empowered (P16, 51, immediate unilateral TRAM).

For many women breast cancer evoked a premature confrontation with mortality, emphasising the transient nature of life. This allowed women to feel fortunate that they were able to survive the disease and thankful they could restore their body image. Subsequently, for some women breast reconstruction altered their outlook on life.

If I am out in a social setting and hear someone moaning about crap (*laughs*) or low-level stuff, I do not say get a life but I often look at people. It has really brought home

to me how precious life is and you should not moan about crap (P16, 51, immediate unilateral TRAM).

Whilst some women described how reconstruction restored their body confidence, a number of women reported changes in body and overall confidence following reconstruction.

I think I am more aware of my body image and I think I lack a bit more confidence regarding my body image (P13, 51, delayed unilateral DIEP).

Around half of the women reported feeling concerned about the potential for breast cancer recurrence. Many of these women attributed their fears to no longer being able to have a mammogram on the affected breast(s). This concern was particularly heightened in women who had been attending routine mammogram appointments every three years for a significant period of time. As this consistent routine provided a source of psychological comfort and this routine changed following reconstruction.

You could have a recurrence on the chest wall and of course you would not feel it, and you cannot mammogram them, so that is a bit of a concern (P4, 67, immediate unilateral LD and implant).

Nevertheless, most women conceptualised reconstruction as a sense of closure to their breast cancer journey that provided a sense of normality, as most women were able to incorporate their new breast into their body image.

Now I have had my breasts reconstructed I feel normal, I feel normal. I would feel maimed without it and it is a silver lining (P9, 47, delayed unilateral DIEP).

Twenty out of twenty-five women suggested they were satisfied with their decision to reconstruct their breast, despite appearance or surgical discomforts. Through making an informed decision, women were able to gain control over their disease, supporting their physical and psychological recovery.

I was 100% happy with the decision I had made and that really helped me (P1, 52, immediate unilateral DIEP).

Most of the women did not express regret with their decision to reconstruct the breast, although a few women suggested elements of regret attributed to restrictive movements, surgical discomfort, fear of recurrence, implant longevity and swift decision making.

I would say slight regret because of the loss of movement, the discomfort and I could have also had something [secondary cancer] on the chest wall. With implants you are a patient of the plastic surgeons for life and the implants will be ten years old shortly, yet I do feel very lucky [to have had reconstruction] (P4, 67, immediate unilateral LD and implant).

Discussion

We have sought to produce an understanding of the experiences of women following post-mastectomy breast reconstruction, in order to identify key components involved in shaping postoperative satisfaction and quality of life. To our knowledge, this is the first study to apply TA to explore the experiences of women following breast reconstruction. TA allowed for the combination of established conceptual themes with rich patient data, through coding for specific and distinct predetermined themes together with more inductive driven codes. Furthermore, the use of TA enabled us to demonstrate that there was only slight variation in some categories of experience among women. The findings from the present study indicate breast reconstruction is an extensive and complex procedure, yet to many women the silver-lining of their cancer journey.

In relation to *quality of life*, many women reported improved emotional functioning and suggested reconstruction allowed them to establish a new normality. Previous qualitative literature also indicates breast reconstruction helps to establish a sense of normality, by allowing women to adapt to their new bodies and identity (Denford et al., 2011). However, some women reported a sense of disconnect and denounced ownership of their breasts. This is inconsistent with qualitative research which suggests reconstruction restores an embodied sense of self (McKean, Newman and Adair 2013). Women also reported poorer functioning in physical, sexual and social domains of quality of life. Although these findings are consistent with some reconstruction literature (Arora et al., 2001; Janz et al., 2005; Nissen et al., 2001, Rowland et al., 2000), the effect of breast reconstruction on quality of life warrants further consideration. Moreover, findings of this study are consistent with previous literature which suggests breast reconstruction is not a universal panacea for the emotional and psychological consequences of mastectomy (Harcourt et al. 2003) but rather a complex and at times rather paradoxical psychological process. Furthermore, a number of women reported debilitating physical side effects following reconstruction. Breast pain was particularly pertinent with implant-based reconstructions and donor site discomfort with autologous-based reconstructions, specifically with TRAM and DIEP procedures. This is consistent with literature which suggests the removal of donor site tissue from its native location weakens the abdominal wall (Ceradini & Levine, 2008). However, autologous-based reconstructions allow for a more natural breast mound in comparison to implant-based reconstructions, as a consequence many women were able to offset their physical discomfort, as they were satisfied with the aesthetic appearance of their breasts.

Many women also experienced a significant decline in the frequency and satisfaction of their sexual functioning following reconstruction, although most women felt their sexual attractiveness returned to their normal levels following reconstruction and some women felt their sexual attractiveness increased. Consequently, we suggest the reported decline of sexual functioning may be partly attributed spousal reaction following reconstruction. As research suggests breast cancer is an interrelated experience for couples, with spouses describing breast reconstruction as an additional stressor (Fasse et al. 2017), which may subsequently affect their level of desire and arousal (Marshall & Kiemle, 2005). This may also be linked to sexual anxiety, specifically in relation to damaging the breasts, inflicting pain and/or

concerns around causing the cancer to return during sexual intercourse (Marshall & Kiemle, 2005). Moreover, qualitative research suggests unconditional spousal support facilitates emotional intimacy following mastectomy without reconstruction (Archer, Holland and Montague, 2016). Therefore, spousal reaction following breast reconstruction requires additional research in order to determine if there is a need for sex-therapy/psychosexual therapy for couples following reconstruction. Furthermore, women were divided with regards to social functioning, with some women reporting improved social functioning and others reporting a lack of self-confidence in social situations following reconstruction. This is consistent with qualitative literature which suggests women often report reduced self-confidence following reconstruction (Abu-Nab & Grunfeld, 2007). Additionally, some women were concerned regarding the perception of others and this sometimes resulted in women concealing their reconstruction due to the fear of appearing vain.

In regards to *breast satisfaction*, most women positively appraised their breast appearance and described realistic appearance expectations. However, three women experienced distress due to the appearance of their breasts. This is consistent with previous research which suggests some women have unresolved and ongoing emotional problems following reconstruction (Murry et al. 2015). Additionally, some women reported improved satisfaction over time due to gradual acceptance of the reconstruction and further corrective surgical procedures. This is in line with current literature which suggests women enter a period of initial physical and psychological adjustment following delayed and even immediate reconstruction (Hill & White, 2008). However, other women described declining appearance satisfaction over time, due to either ptotic nature of autologous-based reconstruction or the fuller projected breast implant-based reconstruction affords. Previous research demonstrates the failure of implant-based reconstruction to naturally ptosis as the patient ages as an area of dissatisfaction (Dutra et al. 2012). However, declining satisfaction due to the ptotic nature of autologous-based reconstruction is a unique finding to this study. This finding also warrants further longitudinal research to ensure clinicians are guiding patients to the most suitable types of surgical technique for short and long term patient satisfaction. Women discussed the inevitability of scarring and nearly all women perceived their scars in a positive manner, as their scars represented their reconstructive journey and signified survival. Similarly, both quantitative and qualitative literature indicates scarring is not a major concern for women following reconstruction (Shakespeare & Hobby, 2001). However, it may be that women who consider scarring as a significant concern would not elect for breast reconstruction (Holland, Archer & Montague, 2014). Women described nipple-areolar complex reconstruction as representing the final chapter of their journey, although often report declining satisfaction over time. Marshall and Kiemle (2005) reported nipple-areolar complex reconstruction is often deemed as the “*finishing touch*” to the breast, allowing the breast to more closely resemble its natural form. Nevertheless, evidence indicates that nipple-areolar complex tattoos are prone to significant fading and often result in patients seeking revisions (Levites et al. 2017). However, only a small proportion of women in this study sought revisions as many described fading as unavoidable.

In the final theme *outcome satisfaction*, nearly all women described feeling satisfied with the outcome of their breast reconstruction, yet in hindsight a number of women would not have opted for reconstruction due to appearance and/or surgery-related discomforts. This is consistent with previous literature, which suggests women often underestimate the obstacles reconstruction presents (Murry et al., 2015), and the enormity of the surgical procedure (Loaring, Larkin, Shaw & Flowers, 2015). Most women had realistic expectations of the recovery period, although some participants described unrealistic recovery expectations in relation to the complexity of the procedure, despite this being emphasised by many of the women's oncologists and plastic surgeons. We suggest healthcare professionals (plastic surgeons, oncologists and breast care nurses) have a crucial role in setting reconstructive expectations, although during this distressing period further psychological support may be required for women to internalise this information. Moreover, healthcare professionals may consider directing women to a clinical decision making tool, such as BRECONDA in order to support breast reconstruction decision making (Sherman et al., 2016). Many women considered breast reconstruction as positively impacting their lives by restoring and in some cases enhancing their confidence, although others reported a decline in confidence following reconstruction. Around half of the women reported concerns of recurrence and many of the women attributed their fears to no longer being able to have a mammogram on the affected breast(s). Women portrayed this fear as yet another anxiety formed from the loss of their "real" breasts. To our knowledge, this finding is novel to our study and may suggest women undergoing breast reconstruction are increasingly likely to experience the fear of recurrence. Nevertheless, twenty out of twenty-five women reaffirmed their decision to undergo reconstruction, suggesting reconstruction provided a sense of normality, closure and a renewed appreciation for life.

Study Limitations

This study yields valuable insights into post-mastectomy breast reconstruction, although there are methodological limitations. Firstly, TA typically affords across case rather than within case analysis, the result of which is a slight loss of the holistic nature of individual experiences. Data generated through TA may appear rather cool and less equipped than other methods to capture fully distressing components of reconstruction such as pain, alienation or loss of intimacy or to explain some of the sophisticated and seemingly paradoxical dimensions of individuals' adaptation and adjustment over time. Nevertheless, TA and the selective use of *a priori* themes allows for the most important measures of surgical success (satisfaction and quality of life) to be captured and the breadth of experience to be recognised. Subsequently, TA is a useful tool in informing clinical practice and outcomes and more specifically for developing interventional support for women following reconstruction. Secondly, the time since reconstruction varied and it is likely that women's experiences and outcomes change over time. Thirdly, given the studies retrospective design it is possible women may not have accurately recounted or may have reframed key aspects of their experiences. However, literature suggests memories of emotionally salient experiences are enhanced over time, arguably mitigating this potential limitation (Yonelinas & Ritchey,

2015). Consequently, future research should consider the experiences of post-mastectomy breast reconstruction patients from a prospective, longitudinal stance.

Clinical Implications

This study provides valuable new insights into post-mastectomy breast reconstruction and extends beyond previous research utilising the qualitative data analysis method, TA. The findings could be used to inform women of the possible outcomes following post-mastectomy breast reconstruction. Moreover, the findings allow researchers and clinicians to focus on specific dimensions of satisfaction and quality of life which require improvement, for example physical, sexual and social functioning, in order to support the needs of women following breast reconstruction. This study also presents two novel findings. Approximately half of women experienced fear surrounding cancer recurrence and this was attributed to no longer being able to have a mammogram on the affected breast(s). This finding may suggest women electing to reconstruct are increasingly likely to experience the fear of recurrence. This finding is unique to the breast reconstruction population, although may also apply generally to mastectomized women. This undoubtedly requires further research to provide appropriate support in order to minimise the fear of recurrence following breast reconstruction. Moreover, the authors reported declining appearance satisfaction over time due to either ptotic nature of autologous-based reconstruction or the fuller projected breast that implant-based reconstruction affords. This finding also warrants further longitudinal research to ensure clinicians are guiding patients to the most suitable types of surgical technique for short and long-term patient satisfaction.

Conclusion

This study identified key factors that are involved in determining satisfaction and quality of life following post-mastectomy breast reconstruction. The study distinguishes between types of satisfaction by exploring breast satisfaction and outcome satisfaction as distinct outcomes. The findings suggest most women were satisfied with their breast appearance and the overall reconstructive outcome following reconstruction. Many women also experienced positive emotional gains and a renewed appreciation for life. However, these gains were often accompanied with substantial deterioration in physical, sexual and social functioning. Nevertheless, most women conceptualised reconstruction as a sense of closure to their breast cancer journey which provided a sense of normality. Future research should consider the experiences of post-mastectomy breast reconstruction patients from a prospective, longitudinal stance.

Acknowledgements

The authors would like to thank all of the women who participated in this study.

References

- Abu-Nab, Z., & Grunfeld, E. A. (2007). Satisfaction with outcome and attitudes towards scarring among women undergoing breast reconstructive surgery. *Patient Education & Counseling*, 66(2), 243-249.

- Alderman, A. K., McMahon, L., & Wilkins, E. G. (2003). The national utilization of immediate and early delayed breast reconstruction and the effect of sociodemographic factors. *Plastic and Reconstructive Surgery*, 111(2), 695-703.
- Al-Ghazal, S., Sully, L., Fallowfield, L., & Blamey, R. W. (2000). The psychological impact of immediate rather than delayed breast reconstruction. *European Journal of Surgical Oncology: The Journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology*, 26(1), 17-19.
- Archer, S., Holland, F.G., & Montague, J. (2016) Do you mean I'm not whole?: Exploring the role of support in women's experiences of mastectomy without reconstruction. *Journal of Health Psychology*, doi: 10.1177/1359105316664135
- Arora, N. K., Gustafson, D. H., Hawkins, R. P., McTavish, F., Cella, D. F., Pingree, S., . . . Mahvi, D. M. (2001). Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: A prospective study. *Cancer*, 92(5), 1288-1298.
- Atisha, D., Alderman, A.K., Lowery, J.C., Kuhn, L.E., Davis, J., & Wilkins, E.G. (2008) 'Prospective analysis of long-term psychosocial outcomes in breast reconstruction: Two-year postoperative results from the Michigan Breast Reconstruction Outcomes Study'. *Annals of Surgery*, 247(6), 1019-28. doi: 10.1097/SLA.0b013e3181728a5c.
- Ballard, T. N. S., Kim, Y., Cohen, W. A., Hamill, J. B., Momoh, A. O., Pusic, A. L., Kim, H. M., & Wilkins, E. G. (2015). Sociodemographic predictors of breast reconstruction procedure choice: analysis of the mastectomy reconstruction outcomes consortium study cohort. *Plastic Surgery International*, 1-9.
- Bar-Meir, E., Eherenfeld, M., & Shoenfeld, Y. (2003). Silicone gel breast implants and connective tissue disease. A comprehensive review. *Autoimmunity*, 36, (4), 193-197.
- Barry, P. N., Riley, E. C., Pan, J., Crew, J. B., Lee, K., Jain, D., Kruse, B., Quillo, A. R., Rai, S., & Dragun, A. E. (2014). Delay of adjuvant chemotherapy after elective mastectomy and immediate reconstruction in breast-conservation candidates: A matched-pair analysis. *American Journal of Clinical Oncology* 37 (6), 575-579.
- Brooks, J., McCluskey, S., Turley, & King, N. (2015). The utility of template analysis in qualitative psychology research. *Qualitative Research in Psychology*, 3, 12(2), 202-222.
- Ceradini, D. J., & Levine, J. P. (2008). Breast cancer reconstruction: More than skin deep. *Primary Psychiatry*, 15(10), 72-80.
- Denford, S., Harcourt, D., Rubin, L., & Pusic, A. (2011). Understanding normality: A qualitative analysis of breast cancer patients concepts of normality after mastectomy and reconstructive surgery. *Psycho-Oncology*, 20(5), 553-558. doi:10.1002/pon.1762

- Dutra, A. K., Neto, M. S., Garcia, E. B., Veiga, D. F., Netto, M. M., Curado, J. H., & Ferreira, L. M. (2012). Patients' satisfaction with immediate breast reconstruction with a latissimus dorsi musculocutaneous flap. *Journal of Plastic Surgery & Hand Surgery*, 46(5), 349-353. doi:10.3109/2000656X.2012.704726
- Fasse, L., Flahault, C., Vioulac, C., Lamore, K., Van Wersch, A., Quintard, B. and Untas, A. (2017). The decision-making process for breast reconstruction after cancer surgery: Representations of heterosexual couples in long-standing relationships. *British Journal of Health Psychology*, 22: 254–269. doi:10.1111/bjhp.12228
- Filiberti, A. Rimoldi, A. Tamburini, M. Callegari, M. Nava, M. Zanini, V. Ventafridda, V. Grisotti, A. (1989). Breast reconstruction: a psychological survey. *European Journal of Plastic Surgery* (2)(12), 214-218.
- Harcourt, D., Rumsey, N., Ambler, N. R., Cawthorn, S. J., Reid, C. D., Madox, P. R., Kenealy, J. M., Rainsbury, R. M. and Umpleby, H. C. (2003). The psychological effect of mastectomy with or without breast reconstruction: a prospective, multi-centre study. *Plastic and Reconstructive Surgery*, 111(3), 1060-1068.
- Hill, O., & White, K. (2008). Exploring women's experiences of TRAM flap breast reconstruction after mastectomy for breast cancer. *Oncology Nursing Forum*, 35(1), 81-88. doi:10.1188/08.ONF.81-88
- Howard-McNatt, M. (2013). Patients opting for breast reconstruction following mastectomy: an analysis of uptake rates and benefit. *Breast Cancer* 5, 9-15.
- Janz, N. K., Mujahid, M., Lantz, P. M., Fagerlin, A., Salem, B., Morrow, M., . . . Katz, S. J. (2005). Population-based study of the relationship of treatment and sociodemographic on quality of life for early stage breast cancer. *Quality of Life Research*, 14(6), 1467.
- Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In G. H. Lerner (Ed.), *Conversation analysis: Studies from the first generation*. ((Ed) ed., pp. 13-31). Amsterdam: John Benjamins.
- King, N. (1998). Template analysis. In G. Symon, & C. Cassell (Eds.), *Qualitative methods and analysis in organizational research*. London: Sage.
- King, N. (2012). Doing template analysis. in *qualitative organizational research: core methods and current challenges*. ed. by Symon, G. and Cassell, C. London: Sage 426-450.
- Klassen, A. F., Pusic, A. L., Scott, A., Klok, J., & Cano, S. J. (2009). Satisfaction and quality of life in women who undergo breast surgery: A qualitative study. *BMC Women's Health*, 9, 1-8. doi:10.1186/1472-6874-9-11
- Lee, C., Sunu, C., & Pignone, M. (2009). Patient-reported outcomes of breast reconstruction after mastectomy: A systematic review. *Journal of the American College of Surgeons*, 209(1), 123-133. doi:10.1016/j.jamcollsurg.2009.02.061

- Levites, H. A., Fourman, M. S., Phillips, B. T., Fromm, I. M., Khan, S. U., Dagum, A. B., & Bui, D. T. (2014). Modeling fade patterns of nipple areola complex tattoos following breast reconstruction. *Annals of Plastic Surgery*, 73 Suppl 2, S153-S156. doi:10.1097/SAP.0000000000000120
- Loaring, J.M., Larkin, M., Shaw, R., & Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: The experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychology*, 34(4), 426-36. doi: 10.1037/hea0000195.
- Marshall, C., & Kiemle, G. (2005). Breast reconstruction following cancer: Its impact on patients' and partners' sexual functioning. *Sexual & Relationship Therapy*, 20(2), 155-179.
- Matthews, H., Carroll, N., Renshaw, D., Turner, A., Park, A., Skillman, J., . . . Grunfeld, E. A. (2017). Predictors of satisfaction and quality of life following post-mastectomy breast reconstruction. *Psycho-Oncology*, doi:10.1002/pon.4397.
- McKean, L. N., Newman, E. F., & Adair, P. (2013). Feeling Like Me again: A Grounded Theory of the Role of Breast Reconstruction Surgery in Self-Image. *European Journal of Cancer Care* 22 (4), 493-502.
- Murray, C. D., Turner, A., Rehan, C., & Kovacs, T. (2015). Satisfaction following immediate breast reconstruction: Experiences in the early post-operative stage. *British Journal of Health Psychology*, 20(3), 579-593.
- National Mastectomy and Breast Reconstruction Audit 2011: A National Audit of Provision and Outcomes of Mastectomy and Breast Reconstruction Surgery for Women in England [online]. available from <https://www.rcseng.ac.uk/surgeons/research/surgical-research/docs/national-mastectomy-and-breastreconstruction-audit-third-report-2010>
- Nissen, M. J., Swenson, K. K., Ritz, L. J., Farrell, J. B., Sladek, M. L., & Lally, R. M. (2001). Quality of life after breast carcinoma surgery: A comparison of three surgical procedures. *Cancer*, 91(7), 1238-1246.
- Noone, R.B., Frazier, T.G., Hayward, C.Z., & Skiles, M.S. (1982). Patient acceptance of immediate reconstruction following mastectomy. *Plastic and Reconstructive Surgery*, 69(4), 632-40.
- Oiz, B. (2005). Breast reconstruction and psychological benefit. *Anales Del Sistema Sanitario De Navarra*, 28 Suppl 2, 19-26.
- Pusic, A.L., Klassen, A.F., Scott, A.M., Klok, J.A., Cordeiro, P.G., & Cano, S.J. (2009). 'Development of a new patient-reported outcome measure for breast surgery: The BREAST-Q.' *Plastic and Reconstructive Surgery*, 124(2), 345-53. doi: 10.1097/PRS.0b013e3181aee807.

- QSR International Pty Ltd. (2015). *NVivo qualitative data analysis software version 11*.
- Rowland, J. H., Desmond, K. A., Meyerowitz, B. E., Belin, T. R., Wyatt, G. E., & Ganz, P. A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors [corrected] [published erratum appears in J NATL CANCER INST 2001 jan 3; 93(1): 68]. *JNCI: Journal of the National Cancer Institute*, 92(17), 1422-1429.
- Shakespeare, V., & Hobby, J. H. (2001). Choices and information offered to patients undergoing immediate post-mastectomy breast reconstruction: A survey of patient opinion and self-assessed outcome. *Breast (Edinburgh, Scotland)*, 10(6), 508-514.
- Shauver, M. J., & Chung, K. C. (2010). A guide to qualitative research in plastic surgery. *Plastic and Reconstructive Surgery*, 126(3), 1089-1097.
doi:10.1097/PRS.0b013e3181e60624.
- Sheehan, J., Sherman, K. A., Lam, T., & Boyages, J. (2007). Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction. *Psycho-Oncology*, 16(4), 342-351.
doi:10.1002/pon.1067
- Sherman, K., Shaw, L.-K., Winch, C., Harcourt, D., Boyages, J., Cameron, L., Brown, P., Lam, T., Elder, D., French, J. and Spillane, A. (2016) Reducing decisional conflict and enhancing satisfaction with information amongst women considering breast reconstruction following mastectomy: Results from the BRECONDA randomized controlled trial. *Plastic and Reconstructive Surgery*, 138 (4). 592e-602e
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
doi:intqhc/mzm042
- Yang, X., Zhu, C., & Gu, Y. (2015). The prognosis of breast cancer patients after mastectomy and immediate breast reconstruction: a meta-analysis. *Plos One* 10 (5), 1-13.
- Yonelinas, A. P., & Ritchey, M. (2015). The slow forgetting of emotional episodic memories: An emotional binding account. *Trends in Cognitive Sciences*, 19(5), 259-267.
doi:10.1016/j.tics.2015.02.009
- Yueh, J. H., Slavin, S. A., Adesiyun, T., Nyame, T. T., Gautam, S., Morris, D. J., . . . Lee, B. T. (2010). Patient satisfaction in postmastectomy breast reconstruction: A comparative evaluation of DIEP, TRAM, latissimus flap, and implant techniques. *Plastic and Reconstructive Surgery*, 125(6), 1585-1595.
doi:10.1097/PRS.0b013e3181cb6351