

Abstract

Most women do not reconstruct their breast(s) post-mastectomy. The experiences of younger women who maintain this decision, although important to understand, are largely absent in the research literature. This interview-based study uses interpretative phenomenological analysis to explore the experiences of six women, diagnosed with primary breast cancer in their 30s/40s, who decided against delayed reconstruction. Findings reported here focus on one superordinate theme (decision-making) from a larger analysis, illustrating that the women's drive to survive clearly influenced their initial decision-making process. Their tenacity in maintaining their decision is highlighted, despite non-reconstruction sometimes being presented negatively by medical teams. Patient-centred support recommendations are made.

Key words: Interpretative phenomenological analysis, reconstruction, breast cancer, mastectomy, decision-making

Introduction

Breast cancer is the most common cancer in women with 1.38 million new cases diagnosed worldwide each year (Jemal et al., 2011). In the UK, there were 49,961 new cases of breast cancer in 2010, with 80% of these in the over 50s (Cancer Research UK, 2013).

Surgery is the mainstay of clinical treatment for breast cancer: in 2007, 82% of all women diagnosed with breast cancer and 90% of those aged under 50 at diagnosis had surgery (Lawrence et al., 2011).. Of those operated on, 57% had breast conserving surgery with the remainder undergoing mastectomy (i.e. the removal of one or both breasts), with immediate or delayed breast reconstruction often considered as part of the treatment regimen (Morrow et al., 2009).

The most recent National Mastectomy and Breast Reconstruction Audit (NHS Information Centre, 2009), reported that 21% of women in the UK undergoing mastectomy chose to have immediate breast reconstruction (a rise of around 10% from the 2005/2006 audit). Of the remainder, 11% opted for delayed reconstruction. Recent US statistics suggest that age is a clear defining factor in relation to reconstruction. Jagsi et al., (2014) suggest that reconstruction rates

for younger American women are between 66.7 % (40-49) and 75.7% (younger than 40), whereas reconstruction rates for those over 50 fall between 48.3% (50-59) and 33.4% (60 plus). Statistics clearly delineating UK reconstruction rates by age group are not readily available.

Breast reconstruction takes one of two forms: using implants or using autologous tissue. In the former, a silicone or saline filled breast implant is inserted beneath the chest muscle during the mastectomy (immediate implant reconstruction) or after a period of healing, often at the conclusion of the cancer treatment. In the autologous method, tissue is taken from one of a number of places in the body e.g. the back, the lower part of the abdomen, the inner thigh or the buttocks. Many women choose not to reconstruct their breast(s); 90% of those who take this route opt to use an external prosthesis (Roberts et al., 2003).

In 2009, the National Institute for Health and Clinical Excellence (NICE) revised its guidance on improving breast cancer outcomes post-surgery, recommending that all women in the UK undergoing mastectomy should be offered the opportunity for breast reconstruction at the point of the initial surgery. Exceptions might occur (e.g. serious co-morbidity, a need for adjuvant treatment, pregnancy or other complicating factors) resulting in a need for information about delayed reconstruction.

Women under 50 seem more likely to be given information about breast reconstruction by their surgeons (Alderman et al., 2008) and to prefer reconstruction (Reaby, 1998; Rowland et al., 2000; Ananian et al., 2004; Finlayson et al., 2001; Jagsi et al., 2014; Sisco et al., 2012). Factors other than age also influence surgical decisions post-mastectomy such as country, region, cancer centre and race/ethnicity (Morrow et al., 2001; Rubin et al., 2013) with input of surgeons also having an effect (Noone et al., 1982; Ananian et al., 2004). Research suggests that referral to a plastic surgeon correlates positively with reconstruction rates even when presenting with late-stage disease (Durrant et al., 2011) and that dual-trained surgeons are more likely to discuss treatment/reconstruction options (Shaterian, 2013).

Decision-making after a cancer diagnosis can be challenging for women. Processing potentially overwhelming amounts of information about diagnosis and treatment (Heller and Miller, 2004), is made in a limited timeframe (Harcourt and

Rumsey, 2004). The medical literature commonly suggests that offering women a reconstruction is surgically optimal (Fang, Shu and Chang 2013; Cromptoets, 2006), especially for younger women (Roje et al., 2010) with studies reporting the psychosocial benefits of reconstruction (Wilkins et al., 2000; Ananian et al., 2004), particularly in terms of immediate versus delayed procedures (Al Ghazal et al., 2000). The picture becomes increasingly complex when pre-existing characteristics such as mental health and body image are considered (Rubino et al., 2007; Krauss, 1999; Figuerido et al., 2004). This complexity appears to be reflected in the rates of reconstruction, which remain below 50% when taken across all epidemiological studies (Alderman et al., 2003), suggesting that despite the assumed psychological benefits of reconstruction (Abu-Nab and Grunfeld, 2007), the majority of breast cancer patients do not reconstruct post-mastectomy.

The extant literature has focused largely on the cosmetic outcomes and perceived benefits of reconstructive surgery; a limited number of qualitative studies focus on reconstruction. Using thematic analysis, Rubin and Tanenbaum (2011) explored how the personal and social contexts of a group of sexual minority women informed their reconstruction decisions. In a further study, Rubin et al., (2013) took a grounded theory approach to better understand why African American women were less likely to reconstruct than the wider American population. In a UK-based study, Truelsen (2003) reported the decision-making of eight women (seven Scottish and one Irish) following mastectomy: four had immediate reconstruction, two delayed their decision and two decided not to reconstruct. For those women choosing not to reconstruct, their reported experiences centred on their relief to be alive. Abu Nab and Grunfeld (2007) and Sheehan et al., (2007, 2008) focused on specific issues in relation to cancer treatment (scarring and regret respectively) and recent, more critical approaches in the area (Harcourt and Rumsey, 2004) suggest that health professionals accept, somewhat unquestioningly, the psychological benefits of reconstructive surgery for women post-mastectomy. This variety of methodological approaches, though addressing extremely important issues for women diagnosed with breast cancer, give a limited view of the cancer experience itself. Interpretative phenomenological analysis (IPA, Smith, Flowers and Larkin, 2009) is designed to do just this: the experience of the woman as told in her own words is foregrounded in the analysis, with convergence and divergence of experiences acknowledged ideographically (Smith et al., 2009).

Prompted by these prior explorations of decision-making around surgery, we explored the process of decision-making of younger UK women when facing mastectomy. As oncology teams have been found to initiate more consultations about reconstruction with their younger patients, we captured the experiences of this group, who had opted not to reconstruct and had maintained their decision over a minimum of five years. To our knowledge no studies have been conducted with this population.

Method

Design

Semi-structured interviews with a purposive, homogenous sample of women were conducted, with resulting transcripts analysed using IPA (Smith, 1996). IPA studies individual perspectives and experiences (Smith, 2004) and is popular in health psychology (Brocki and Wearden, 2006; Smith et al., 2009). It has been used in recent US-based studies exploring women’s experiences of breast cancer (Vilhauer, 2011; McDonough, Sabiston and Crocker, 2008).

Participants and Recruitment

Women diagnosed with primary breast cancer under the age of 50, who were at least five years post-diagnosis and had elected to not reconstruct their breast(s) post-mastectomy, were recruited. Recruitment was conducted via a breast cancer charity web forum. Seven women responded to the advert. All were given an invitation to participate and were sent a copy of the questions in advance. Of the seven, six participated in the study. Although not part of our inclusion criteria, none of these participants were eligible for immediate reconstruction due to adjuvant treatment (and pregnancy in one case) but all were candidates for delayed reconstruction. The age of the women at diagnosis ranged from 31-46 years (median: 38.6). All lived and were treated in England. Table 1 outlines participant information.

Name*	Age at diagnosis	Partnership status at diagnosis	Motherhood status at diagnosis
Eloise	32	Married	2 children

Paula	40	Married	1 child
Sarah	39	Male partner	Information withheld
Anya	46	Single	1 child
Rebecca	31	Married	Pregnant with first child
Maureen	44	Married	n/a

* pseudonym

Table 1: Participant information

The study conformed to the British Psychological Society's (2009) ethical standards and a university psychology ethics committee granted approval. Participants gave full and informed consent and were aware that the interviewer was an academic researcher rather than a clinician. Participants received a £20 shopping voucher for their participation.

Materials and procedure

Interviews (audio-recorded via Skype™), lasted between 30-60 minutes, with a laptop being used to 'telephone' each participant who talked via their phone; web cameras were not used. Telephone interviews were used to maximise the convenience for the women who lived across a wide geographical area. This method has been found to complement qualitative data analysis methods (Cachia and Milward, 2011) and has been used successfully in IPA research (Swift and Wilson, 2001). Interviews were transcribed verbatim; pseudonyms were used in all notes, transcripts and analyses. The interviewer was female and of a similar age to the participants. A schedule of broad, non-directive, open-ended questions guided discussions about the women's lived experience, in particular their decision not to reconstruct post-mastectomy. Questions were informed by existing research, for example: a) Can you tell me a little about yourself and how you came to have a mastectomy? b) Can you tell me about the process that led you to choose to not reconstruct after your mastectomy? Did you discuss this choice with others? If so, who? c) Did your choice to not reconstruct have any effect on your relationships with other people? d) Before you had the mastectomy, how would you describe your relationship with your body? Do you

feel that there were any changes in this relationship with your body once you had had the mastectomy? It is acknowledged that the authors were all female, qualitative researchers with a variety of critical health, social psychology and health promotion backgrounds.

Data Analysis

All authors read through transcripts independently before undertaking a collaborative, line-by-line coding of each. Linguistic elements, e.g. metaphor and pronoun use, were noted (Shinebourne and Smith, 2010). Narrative summaries were developed for participants, with quotes used to highlight emergent themes. Convergent and divergent quotes were included producing a comprehensive cross-case analysis. Final theme and sub-theme selection was guided by Smith's (2011) recommendations for high quality IPA, including prevalence (occurrence of themes across all interviews), representativeness (of all participants) and variation (the full range of experiences). The following analysis represents part of a larger body covering topics such as identity and familial/social support. Here, we focus on one superordinate theme, namely *Decisions around non-reconstruction*. Sub-themes entitled (1) *Making the decision: Cutting it out*; (2) *Maintaining the decision: Living as a one breasted woman in a two breasted world* and (3) *Defending the decision: 'I'm happy enough without it'* illustrate our interpretation of experience before, during and after mastectomy.

Results

(1) *Making the decision: Cutting it out*

After diagnosis, mastectomy was the recommended treatment for five of the women. The sixth, Eloise, was offered either lumpectomy or mastectomy and given time to decide. She elected the latter, describing herself as being 'adamant from the start' and telling her surgeon, 'I want a mastectomy, I want it got rid of'.

Eloise was determined to maximise her survival by opting for the more aggressive surgical option. She felt relief and was 'just concerned to be healthy for [her] children'. This drive to survive was clearly represented across the accounts. The women moved very quickly into a pragmatic, survival-focused mode after the initial shock of diagnosis: the breast became a sacrifice to eradicate any chance of the cancer remaining in their bodies, and the breast and

cancer became synonymous. 'Cutting it out and getting rid of it' (Rebecca) was seen to enhance their chances of survival.

During initial consultations with medical teams, both treatment and reconstruction were discussed. For the majority of these women, although immediate reconstruction was not an option, future reconstructive surgery was often a focus of consultations and promoted as a normative process post-mastectomy:

It's very much have the operation and have the reconstruction straight away and then deal with the consequences afterwards. Well, in amongst all of the angst of having been told you've got cancer and being told that's the way to deal with it, you would go along with it, when in fact it's not necessarily a step that needs to be taken (Rebecca).

The option of immediate reconstruction was positioned for some as part of the expected course of treatment and the sense of being a cooperative (and passive) patient was evident in Rebecca's words. Several of the women reported this on-going discussion with their medical teams. They reported its potential to perhaps lead to some women feeling a sense of pressure around the decision while still experiencing the 'angst' accompanying the diagnosis. For these women, however, the responses to this perceived pressure were mixed; some reported being sure about not reconstructing from the point of diagnosis; others discussed the initial attractiveness of reconstruction. As it became apparent that immediate reconstruction was not a viable surgical option due to their diagnosis, however, the additional time offered between mastectomy and potential reconstruction provided an opportunity to think, gather information and evaluate their individual circumstances to help them make a more informed, rationalised decision.

In some cases, there appeared to be a lack of information provided about life post-mastectomy *without* reconstruction; the majority of resources available from both formal and informal sources, tended to focus on reconstruction:

I wasn't given a sheet that said what it is like if you don't have one [reconstruction] I mean I think there was something given to me along the way that said you can have prosthetic breasts and all this sort of

stuff but I think quite a lot of that stuff I figured out doing my own research (Paula).

Some of the women expressed a desire to see a post-mastectomy body that had not undergone reconstruction, either in the form of photographs or by seeing real women in the flesh – ideally someone who had maintained their decision not to reconstruct over time. They had been given or had been able to source information about reconstruction options and outcomes; they perceived that this was more freely available than the non-reconstruction route. A sense of isolation and marginalisation as a younger woman wanting to seek out resources around non-reconstruction was evident. Paula, for example, spoke with a 70 year old about the woman's choice surrounding non-reconstruction, but did not feel comfortable to ask to see her mastectomy site. Paula reported that she went online to find more images but found that 'there was not really anything at all'. For participants who were able to find images of reconstructed breasts, they seemed generally unappealing and some responded negatively to them:

I would certainly not go through all that to have something that didn't look natural and just to make me look, just to make me balance better on the other side (Anya).

The relationship with their own breasts as 'natural' directly contrasts with their expectations of reconstruction: they were under no illusion that a reconstructed breast would be 'other'. Sarah said, 'it looks like a breast but isn't a breast'. This unnatural replacement was described in stark language highlighting its 'otherness':

What you've got on your chest is a numb piece of fat from your stomach (Sarah).

Even an autologous reconstruction was distanced as alien:

I thought they looked, even those you know that had been reconstructed from flesh and muscle taken from the back and then twisted and had a nipple tattooed on and all the rest of it, it just did not look natural (Anya).

The women's own breasts are depicted as functional but also dispensable, due to their diseased state. For example, Anya reported her breast as having 'done its duty' as she had breastfed her daughter. Rebecca experienced her diagnosis

while she was pregnant with her first child and she was only able to breast feed for four weeks before her mastectomy. This, however, was not perceived negatively; Rebecca stated that she 'wasn't particularly bothered about that [early weaning]' because her drive to survive was dominant. The breast was viewed as part of a much larger whole. Eloise said:

It is only a breast at the end of the day and you know it's not a vital organ (Eloise).

A similar attitude was voiced by Paula:

I likened it to, you know, if I was going to lose an arm, that would probably have quite a big effect on my life and I would not want to do that but to lose a breast, its not a disability, it doesn't actually impact that much on my life (Paula).

The women did not describe reconstruction positively and the magnitude of the extra surgery was recognised:

I know having a reconstruction isn't an illness, but it's a big haul isn't it? It's bigger than the initial operation, especially when you have it done at a different time (Maureen).

These women felt their bodies had been through enough and were unwilling to pursue additional elective procedures which were viewed as cosmetic and inessential to their survival and quality of life.

(2) Maintaining the decision: Living as a one-breasted woman in a two-breasted world

Once the decision to not reconstruct had been made, some of the women reported questioning of their decision or pressure to reconsider their one-breastedness as a long-term decision. The pro-reconstruction messages reportedly received from some healthcare teams, particularly from surgeons, sometimes seem to have been prompted by the fact that the women were younger at diagnosis. These messages continued after the initial diagnosis and treatment in follow-up conversations:

There was a senior registrar who was there with a consultant who talked to me about it, who was very much keen, you know you're a

young woman, do you want to go through the rest of your life without something there? (Sarah).

For Sarah, reconstruction was presented as the optimal choice and it was assumed to be something she would want. In Sarah's account, it was reported that the senior registrar drew attention to her age, and his keenness for her to agree to reconstruction seemed to be tied to that. Not pursuing reconstruction was positioned by some participants as being an unattractive option and a 'hard sell' and sense of coercion was identified:

Yeah, why don't you go along with this? But, I suppose, but his specialism was reconstruction, that was his thing so I suppose if that's what you do, you can't see why someone won't pursue it (Maureen).

A perceived paternalistic model of care and lack of patient-centred practice was evident in some of the women's accounts. Anya and Rebecca, however, (who both had complicating factors in their diagnoses: poor initial prognosis and pregnancy respectively) described interactions with their surgeons more positively than the other participants. This might be due to the lack of options available when diagnosed which led to their surgeons deferring any discussion about reconstruction, although Anya's mastectomy enabled reconstruction to be more easily completed at a later date:

There was a bit of a sort of flap under my armpit, he said we can neaten that up for you if you like and I said, well, no, I don't want any more bits taken off thank you very much and I told the surgeon about it and he said, well, we did that in case you wanted a reconstruction because it would help, you know because there's more flesh there to do it, but only as a sort of side line (Anya).

Anya reported that the surgical priming of her body for reconstruction when her breast was removed was not discussed with her until she asked about it afterwards, and then only in passing. The assumption that she might want to pursue reconstruction at a later date seems to position her in a passive, cooperative patient role and adds emphasis to the idea that the one breasted body would not be an option given a choice.

Interactions with their breast care nurses were described by the women as taking a more counselling-focused tone than those with surgeons. However, despite

feeling more supported in these conversations, Sarah and Maureen felt that nurses and support group facilitators were still generally pro-reconstruction:

Even though as part of the job I think they have to give the facts, I think quite a lot of them, just meeting them through support groups and things, think that reconstruction is a good thing and the be-all and end-all and that they'd have it done and I came across an awful lot of that (Sarah).

There's more discussion about pros and cons of reconstruction than of not [having reconstruction] (Maureen).

Both women suggest that rather than having a balanced discussion, they experienced interactions that were generally weighted towards reconstruction. Sarah indicates that this is not the only message given, and at a different point in her interview, she discusses how the reality of living with a reconstructed breast was highlighted by one of her nurses::

Well, you know you're not going to get exactly what you've had taken away, it's going to feel different, you know, you may not have any feeling at all in it, although it can look good cosmetically, there are all sorts of problems around having it [reconstruction] done (Sarah).

The women all described a pragmatic relationship with their breasts and towards reconstruction. Anya summarised, 'you've still lost a breast whether you've got a reconstructed one or not'. The women's drive to survive, recognition of the big picture and their understanding that replacing a breast cosmetically was a superficial augmentation of their body was clearly evident throughout their accounts.

(3) Defending the decision: 'I'm happy enough without it'

Some of the women described having to defend their decision not to reconstruct multiple times to their medical team who continued to question this:

I went to the hospital and they did discuss it with me and say, are you sure? At that point I was definitely I know what I was doing I knew what I wanted so they kind of gave up (Paula).

It was only through persistence and tenacity that these women felt their decision was finally accepted. They were proactive in their commitment to their decision and in their defensive stance their agency and self-advocacy was highlighted. The culmination of this experience of making, maintaining and defending their decision to not reconstruct left the women with a sense of being in the minority – of going against the perceived norm of reconstruction.

I felt sometimes that I was like being a bit odd by not having it, but I was totally 100% confident in myself, in knowing what I didn't want so it might have been a bit easier if they'd just said, right, if that's your decision yeah, that's absolutely fine and let's look at what you can do to make that, the not having a reconstruction a good experience (Maureen).

Maureen desired that non-reconstruction be seen as a viable choice with positive support rather than a non-choice, leaving some of the women cast in the role of an outsider or considered a difficult patient. Maureen suggested that support and agreement was not immediately forthcoming, meaning that her experience was one of difficulty and anxiety.

An unwillingness to endure additional elected reconstructive surgery for a number of reasons was evident in these women's accounts. Sarah represented this viewpoint:

My body's as it was with a bit missing that's been taken away because there was something wrong with it, so I'm as I was, why go through all this rigmarole when, you know, I'm happy enough without? (Sarah).

The women's self-advocacy speaks to their tenacity and resilience as they made, maintained and, in some cases, defended their decision not to reconstruct. Despite some of the women encountering difficulties in gaining support from health care practitioners for the decisions they made,, their sense of wholeness was maintained. The experience of making these decisions was emotional and anxiety provoking; this emotion appeared to be less tied to the loss of the breast itself and more to the processes of having their decision supported.

Discussion

As discussed, rates of reconstruction in the UK are rising (NHS Information Centre, 2009); however, the majority of women across all age groups do not

reconstruct post-mastectomy (Alderman et al., 2003). Although UK reconstruction rates by age are presently unclear, the women in this study perceived themselves to be going *against* a norm. This might possibly be due to their younger age at diagnosis. Surgeons are suggested to deliver pro-reconstruction information to younger breast cancer patients (Alderman et al., 2008), and this group are more likely to choose this surgical option (Reaby, 1998; Rowland et al., 2000; Ananian et al., 2004; Finlayson et al., 2001, Jagsi et al., 2014). It is suggested by some of our participants that their medical teams assumed that they, as younger women, would prefer reconstruction even as a delayed option. This is consistent with some of Rubin and Tanenbaum's (2011) participants who were initially against reconstruction but were persuaded by their medical teams to proceed with it. In some cases, therefore, it is apparent that information may be delivered with a pro-reconstruction slant. This may be based on the largely uncritical understandings of the extant literature.

As previously highlighted, studies exploring women's satisfaction with their decision to reconstruct or not following mastectomy reveal no significant difference over time; viewing reconstruction as a 'universal panacea' for emotional and psychological recovery after mastectomy should therefore be carefully considered by those in cancer care (Harcourt et al, 2003). This critique is echoed in Sheehan and colleagues' research (2007, 2008) exploring regret after decision-making around reconstruction. Previous studies have indicated a number of variables associated with the uptake of breast reconstruction (Morrow et al., 2001; Rubin and Tanenbaum, 2011; Rubin et al., 2013) e.g. race, ethnicity, sexual orientation, spiritual beliefs). We suggest, therefore, that tacit understanding of the psychological implications of reconstruction would benefit from further exploration by clinicians and researchers. A failure to do this may result in faulty assumptions and, perhaps, unsupported pro-reconstruction biases. We acknowledge that the women in our study may be defending their decision to not reconstruct; however, this may also be the case for those women who do reconstruct without regret.

Women in the US have the highest rates of reconstruction (56% regardless of age: Jagsi et al., 2014). The women in our sample were located across England. We did not explore whether their age affected the level and type of information they were given by their medical teams, but some of them described feeling 'odd' by not pursuing reconstruction. This echoes prior research where younger

women seem more likely to choose reconstruction (Reaby, 1998; Rowland et al., 2000; Finlayson et al., 2001; Ananian et al., 2004, Jagsi et al., 2014).

Qualitative research focusing on decision-making around (non-) reconstruction after breast cancer is limited and no papers exploring younger women's experiences relating to decision-making in this area have been conducted with a UK population. Similarly, no published studies focus only on women who have maintained the decision to not reconstruct over time. The study reported here contributes to an emerging body of literature, and introduces an English National Health Service context. Limitations should be acknowledged. The sample size is small yet consistent with other IPA studies. It is recognised that women from different socio-economic, geographic and ethnic backgrounds may have different experiences. Additionally, women's age and relationship status should be considered in future research. Our participants were not eligible for immediate reconstruction therefore this narrowed the focus of our work to delayed reconstruction only. We acknowledge that had immediate reconstruction been an option, their decisions may have been different. In line with much of the previous research, the study reported here is retrospective in nature, with women being interviewed at least five years after their diagnosis. The women have, therefore, had time to adjust and reflect upon their situation.

Conclusion

For this group of women delayed reconstruction was dis-preferred for a variety of reasons including additional healing and hassle, unwillingness to have unnecessary cosmetic procedures, wishing to self-examine their bodies without obstruction and perceiving reconstruction negatively. Although they acknowledged reconstruction as a valid option for some, they suggested that it should not be assumed that all women, even if younger, would want it. Recommendations from this study include increasing the resources available that educate and support non-reconstruction as a permanent and acknowledged option, even for younger women. Our participants suggested that seeing and being able to talk with similar aged women who had engaged in both reconstruction and non-reconstruction would have positively informed their decision-making process and decreased their sense of isolation and going against the perceived 'norm' of reconstruction. The experience of having an extended period to consider their surgical options (because they were not eligible for immediate reconstruction) was reported as being extremely helpful.

Some of the women acknowledged that if they had been eligible for immediate reconstruction, this might have been chosen due to the time pressure to make a decision, the positive positioning of option by the medical teams and its initial attractiveness. However, the additional time that delayed reconstruction provided enabled them to feel less pressured; they could research their options, adjust to their situation, and were able to make a more considered decision. In addition, it should be noted that this group of women all described positive support from their immediate social networks, which also reinforced the decision making process. It is acknowledged that the findings may link with previous research in the broader area of social representations of the body. This will be explored more fully in a later paper. Although the decision making phenomenon has been studied previously in a variety of contexts, the focus of this paper is to provide insight into the lived experience of women based in the UK to add to the studies in the area of mastectomy and reconstruction.

This group of women acknowledged the need for positive messages regarding non-reconstruction from their medical teams and within the formal resources provided for them. In addition, informal literature, images and media coverage were perceived to lack the positive representation of non-reconstructed bodies. Non-reconstruction, therefore, was not encountered in a balanced way by these younger women; in some cases, this was reported to negatively affect relationships with their medical teams. As these women were diagnosed at least five years ago, information available to women facing mastectomy now may be more comprehensive. Some of these women highlighted the need for additional, independent counselling to support the decision-making process; a person-centred approach to this would be ideal. Also, practical information around prostheses, navigating relationships and accepting their new normal were discussed as necessary to promote a more positive experience. In moving forward, it is recommended that medical teams and breast cancer support services review and reflect upon their current practice and beliefs about the reconstruction process for women of all ages facing mastectomy. More information about the pros and cons of immediate and delayed reconstruction, a balanced view that does not assume that younger women will automatically choose reconstruction and clearer statistics around reconstruction rates for all women, would be positive changes for medical teams to make. It is also recommended that future research explores the decision-making processes and post-mastectomy experiences of women from different ethnic and socio-cultural

backgrounds across all age groups. This will help to build a broader base of understanding about women's experiences when facing breast cancer surgery. Additionally, using IPA to explore the lived experiences of younger women who have elected to reconstruct their breast/s post-mastectomy (either immediate or delayed) will positively contribute to this understanding.

References

- Abu-Nab Z and Grunfeld EA (2007) Satisfaction with outcome and attitudes towards scarring among women undergoing breast reconstructive surgery. *Patient Education and Counselling*, 66:243–249.
- Alderman, AK, Hawley, ST, Waljee, J, Mujahid, M, Morrow, M, and Katz, J (2008) Understanding the impact of breast reconstruction on the surgical decision-making process for breast cancer. *Cancer*, 112, 489–494.
- Alderman A K, McMahon L, and Wilkins, EG (2003) The national utilization of immediate and early delayed breast reconstruction and the impact of sociodemographic factors. *Journal of Plastic and Reconstructive Surgery*, 11: 695–703.
- Al-Ghazal SK, Sully L, Fallowfield L and Blamey RW (2000) The Psychological Impact of Immediate Rather than Delayed Breast Reconstruction. *European Journal of Surgical Oncology*, 26: 17-19.
- Ananian P, Houvenaeghel G, Protiere C, Rouanet P, Arnaud S, Moatti JP, Tallet A, Braid AC, and Julian-Reynier C (2004) Determinants of patients' choice of reconstruction with mastectomy for primary breast cancer. *Annals of Surgical Oncology*, 11(8): 762-771.
- British Psychological Society (2009) *Code of Ethics and Conduct*. British Psychological Society: Leicester.
- Brocki JJM and Weardon A J (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1): 87-108.
- Cancer Research UK (2013). *Breast Cancer Incidence Statistics*. Available at: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/breast/incidence/uk-breast-cancer-incidence-statistics> (accessed 01/11/2013).
- Ceradini DJ and Levine JP (2008) Breast cancer reconstruction: More than skin deep. *Primary Psychiatry*, 15:72–80.

[Cordeiro PG](#) (2008) Breast reconstruction after surgery for breast cancer. [New England Journal of Medicine](#), 359(15): 1590-601.

Cachia M and Milward L (2011) The telephone medium and semi-structured interviews: A complementary fit. *Qualitative Research in Organisations and Management: An International Journal*, 6 (3): 265-277.

Crompvoets S (2006) Comfort, control, or conformity: women who choose breast reconstruction following mastectomy. *Health Care Women International*, 27: 75–93.

[Durrant CA](#), [Khatib M](#), [Macneill F](#), [James S](#), and [Harris P](#) (2011) Mastectomy and reconstruction in stage IV breast cancer: a survey of UK breast and plastic surgeons. *Breast*, 20(4): 373-9.

Fang S, Shu B and Chang Y (2013) The effect of breast reconstruction surgery on body image among women after mastectomy: A meta-analysis. *Breast Cancer Research and Treatment*, 137: 13–21.

Figueiredo ML, Cullen J, Hwag Y, Rowland JH and Mandelblatt JS (2004) Breast cancer treatment in older women: Does getting what you want improve your long-term body image and mental health? *Journal of Clinical Oncology*, 22(10): 4002 – 4009.

Finlayson CA, MacDermott TA and Arya J (2001) Can specific preoperative counselling increase the likelihood a woman will choose post mastectomy breast reconstruction? *The American Journal of Surgery*, 182(6): 649-653.

Harcourt D and Rumsey N (2001) Psychological aspects of breast reconstruction: A review of the literature. *Journal of Advanced Nursing*, 35(4): 477-487.

Harcourt D and Rumsey N(2004) Mastectomy patients' decision making for or against immediate breast reconstruction. *Psycho-Oncology*, 13:106–115.

Harcourt D, Rumsey NJ, Ambler NR, Cawthorn SJ, Reid C, Maddox P, Kenealy JM, Rainsbury RM, Umpleby, H (2003) The psychological effect of mastectomy with or without breast reconstruction: A prospective, multicenter study. *Plastic and Reconstructive Surgery*, 11: 160–168.

Heller L. and Miller MJ (2004) Patient Education and Decision Making in Breast Reconstruction. *Seminars in Plastic Surgery*, 18(2): 139-147.

[Jagsi R](#), [Jiang J](#), [Momoh AO](#), [Alderman A](#), [Giordano SH](#), [Buchholz TA](#), [Kronowitz SJ](#) and [Smith BD](#) (2014) Trends and Variation in Use of Breast Reconstruction in Patients With Breast Cancer Undergoing Mastectomy in the United States. *Journal of Clinical Oncology*, 32(9): 919-926. DOI 10.1200/JCO.2013.52.2284.

Jahkola T, Asko-Seljavaara S, and von Smitten K (2003) Immediate breast reconstruction. *Scandinavian Journal of Surgery*, 92: 249–256.

[Jemal A](#), [Bray F](#), [Center MM](#), [Ferlay J](#), [Ward E](#) and [Forman D](#) (2011) Global Cancer Statistics. *CA: A Cancer Journal for Clinicians*, 61(2): 69-90.

Kraus PL (1999) Body image, decision making, and breast cancer treatment. *Cancer Nursing*, 22(6): 421 – 427.

Lawrence G, Kearins O, Lagord C, Cheung S, Sidhu J, Sagar C (2011) *The Second All Breast Cancer Report*. National Cancer Intelligence Network: London.

McDonough M, Sabiston CM and Crocker, PRE (2008) An Interpretative phenomenological examination of psychosocial changes among breast cancer survivors in their first season of dragon boating. *Journal of Applied Sport Psychology*, 20, 425-440.

Morrow M, Jagsi R, Alderman A, Griggs JJ, Hawley ST, Hamilton AS, Graff JJ, Katz, SJ (2009) Surgeon recommendations and receipt of mastectomy for treatment of breast cancer. *JAMA*, 302(14): 1551-1556.

Morrow M, Scott SK, Menck HR, Mustoe TA and Winchester, DP (2001) Factors influencing the use of breast reconstruction postmastectomy: A National Cancer Database study. *Journal of the American College of Surgeons*, 192(1): 1–8.

National Institute for Health and Clinical Excellence (NICE) (2009). *Early and Locally Advanced Breast Cancer: Diagnosis and Treatment*. National Collaborating Centre for Cancer: Cardiff, Wales.

Neill KM, Armstrong N and Burnett CB (1998) Choosing reconstruction after mastectomy: A qualitative analysis. *Oncology Nursing Forum*, 25: 743–750.

NHS: The Information Centre for Health and Social Care (2009). *National Mastectomy and Breast Reconstruction Audit*. NHS Information Centre, London.

Nissen MJ, Swenson KK and Kind EA (2002) Quality of life after postmastectomy breast reconstruction. *Oncology Nursing Forum*, 29: 547–553.

Noone RB, Frazier TG, Hayward CZ and Skiles MS (1982) Patient acceptance of immediate reconstruction following mastectomy. *Plastic and Reconstructive Surgery*, 69: 632-638.

Reaby LL (1998) Reasons why women who have mastectomy decide to have or not to have breast reconstruction. *Plastic and Reconstructive Surgery*, 101(7): 1810–1818.

Roberts S, Livingston, P, White, V and Gibbs, A (2003) External breast prosthesis use: Experiences and views of women with breast cancer, breast care nurses and prosthesis fitters. *Cancer Nursing*, 26(3): 179-186.

Roje Z, Roje Z, Jankovic S and Ninkovic M. (2010). Breast Reconstruction after Mastectomy. *Coll. Antropol*, S1: 113-123.

Rowland JH, Desmond KA, Meyerowitz BE, Belin TR, Wyatt GE and Ganz PA (2000) Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. *Journal of the National Cancer Institute*, 92(17): 1422–1429.

Rubin LR, Chavez J, Alderman A and Pusic AL (2013) ‘Use what God has given me’: Difference and disparity in breast reconstruction *Psychology and Health*, 28(10): 1099-1120.

Rubin LR and Tanenbaum M (2011) “Does that make me a woman?”: Breast cancer, mastectomy, and breast reconstruction decisions among sexual minority women. *Psychology of Women Quarterly*, 35(3): 401-414.

Rubino C, Figus A, Loretto L and Sechi G (2007). Post-mastectomy Reconstruction: a Comparative Analysis on Psychosocial and Psychopathological Outcomes. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 60: 509-518.

Sheehan J, Sherman KA, Lam T and Boyages J (2007) Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction. *Psycho-Oncology*, 16: 342-351.

Sheehan J, Sherman KA, Lam T and Boyages J (2008) Regret associated with the decision for breast reconstruction: The association of negative body image, distress and surgery characteristics with decision regret. *Psychology & Health*, 23(2): 207-219.

[Shaterian A](#), [Saba SC](#), [Yee B](#), [Tokin C](#), [Mailey B](#), [Dobke MK](#) and [Wallace AM](#) (2013) Single dual-trained surgeon for breast care leads to higher reconstruction rates after mastectomy. *World Journal of Surgery*, 37(11): 2600-2006.

Sisco M, Du H, Warner J. P, Howard MA, Winchester DP and Yao K (2012) Have we expanded the equitable delivery of postmastectomy breast reconstruction in the new millennium? Evidence from the national cancer data base. *Journal of the American College of Surgeons*, 215(5): 658-666.

Shinebourne P and Smith, JA (2010) The communicative power of metaphors: An analysis and interpretation of metaphors in accounts of the experience of addiction. *Psychology and Psychotherapy: Theory, Research and Practice*, 83: 59-73.

Smith JA (1996) Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11: 261-271.

Smith JA (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1): 39-54.

Smith JA (2011) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1): 9-27.

Smith JA, Flowers P and Larkin M (2009) *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage Publications.

Swift TL and Wilson SL (2001) Misconceptions about brain injury among the general public and non-expert health professionals: An exploratory study. *Brain Injury*, 15 (2): 149-165.

Vilhauer, RP (2011) 'Them' and 'us': The experiences of women with metastatic disease in mixed-stage versus stage-specific breast cancer support groups. *Psychology and Health*, 26 (6): 781-797.

Wilkins EG, Cederna PS, Lowery JC, Davis JA, Kim HM, Roth RS, Goldfarb S, Izenburg PH, Houin HP and Shaheen KW (2000) Prospective Analysis of Psychosocial Outcomes in Breast Reconstruction: One Year Postoperative Results from the Michigan Breast Reconstruction Outcome Study. *Plastic and Reconstructive Surgery*, 106(5): 1014-1025.