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Patients' and Providers' Experiences with Breast Implants: A Rapid Qualitative Review

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Context and Policy Issues

Breast implants are used for a variety of different purposes and used by different populations. Breast implants can be used to reconstruct breasts after mastectomies due to breast cancer. Breast implants can be used to correct breast abnormalities such as breast asymmetry. Breast implants may also be used for aesthetic reasons to enhance the cosmetic appearance. Those who are born as biological males but who identify as female can also opt for breast implants.

How each of these populations makes decisions about breast implants is likely to be different. In addition, given links between breasts and femininity and attractiveness, it is likely that these decisions may vary by social location and culture such as by ethnicity, religiosity, income etc. The purpose of this review will be to develop a better understanding of how people make decisions about breast implants and what factors influence this decision, from the perspective of individuals who may undergo surgery as well as their healthcare providers.

This review will also explore how individuals feel about their breast reconstruction postsurgery. How do individuals evaluate the success of the intervention? What factors influence individual's notion of a successful outcome? Do individuals report different types of experiences depending on the type of implants that were used in the surgery? How is success defined and constructed for different individuals?

Research Question

What are the experiences' and perspectives' of patients who receive breast implants, and their providers who offer them?

Key Findings

Women who had breast reconstruction due to asymmetrical breasts described how their condition made them feel not normal and unfeminine. Post-surgery, women described increased feelings of self-confidence and that they were more comfortable wearing fitted clothes, going out and revealing their unclothed body to partners. Women tended to be secretive about the reason for their breast reconstruction surgery. Reasons for secrecy that were offered by the participants included not wanting to be viewed as "weird" and that the condition and its treatment are not well-known.

Many themes emerged when researchers explored how women with breast cancer, and then a mastectomy, make decisions about breast reconstruction. Women spoke about the meaning of their breasts to themselves and to their sense of identity. Notions of femininity, normalcy and the natural body varied amongst women and influenced their views on breast reconstruction. For instance, women who had an ethos of the natural body chose not to have reconstructive surgery or chose autologous breast reconstruction, as the latter did not involve foreign materials in the body. Women sometimes chose breast implants because it restored a normal appearance and did not involve pain in multiple sites (compared to autologous reconstruction). These perceptions and views were shaped by the cultural and social context of the women's lives. Women's choices about breast reconstruction were also influenced by their views on the alternative (e.g. breast prostheses), their views on the surgical procedure and on the views of their community, family and medical team. Medical



teams raised the issue of breast reconstruction, often early in the course of treatment. Sometimes these options were framed by notions of personalized care. However, data from interviews with women and health care professionals in the UK and in France suggest that sometimes these options were framed based on the expertise and availability of treatment options at the clinic and the perspective of the surgeon, rather than on the needs and perspective of the woman.

Women who were satisfied with the outcome of surgery felt that it satisfied or exceeded expectations. Whereas those who were disappointed reported that the outcome was not as good as they had anticipated, or they felt that that they had not been fully informed about all the options available to them, No literature was found that distinguished the experience of women who received different types of implants (e.g. saline vs silicone). There was no research that was found that described the perspectives of health care professionals about their preferences or decision-making among different type of breast implants. The only literature describing health care professional perspectives concerns their views on the inadequacy of information offered to women about treatment options.

Methods

Literature Search Methods

A limited literature search was conducted on key resources including Medline, the Cumulative Index to Nursing & Allied Health Literature (CINAHL), the Cochrane Library, University of York Centre for Reviews and Dissemination (CRD) databases, Canadian and major international health technology agencies, as well as a focused Internet search. A focused search for qualitative studies or surveys was conducted. For this search, main concepts appeared in title, abstract, or major subject heading and a qualitative studies filter was applied. The search was limited to English language documents published between January 1, 2013 and July 13, 2018.

Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

Table 1: Selection Criteria

| Population | Patient receiving breast implants for any reason Providers who perform breast implants for any reason |
|---------------|---|
| Intervention | Breast implants and expanders |
| Comparator | Not applicable |
| Outcomes | Patients' and providers' experiences and perspectives on: decision making; surgery and recovery (complications); clinical interactions; expectations of surgery; on outcomes of surgery; other issues that emerge as important during the review |
| Study Designs | Qualitative studies defined as studies using methods for collecting qualitative data (i.e., focus groups, interviews, text, observation) or using a type of interpretive analysis (e.g., thematic analysis, content analysis), the qualitative component of mixed methods studies, and qualitative or mixed method literature reviews |



Exclusion Criteria

Articles were excluded if they were not published in English or did not meet the selection criteria outlined in Table 1.

Critical Appraisal of Individual Studies

The included studies were critically appraised by one reviewer using the Critical Appraisal Skills Programme Qualitative Checklist.¹

Data Analysis

One reviewer conducted the analysis, using Nivo9 from QSR international² to manage the data. Initial codes identified themes and concepts raised in the research. Codes were then lumped into conceptual categories to create new themes addressing the research questions, which form the basis of this report. Themes that were reiterated across numerous studies are emphasized, with attempts made to explain the thematic results that emerged.

The experiences of women with asymmetrical breasts and those who had mastectomies due to breast cancer are presented separately, as the starting point is different. The former group sought breast reconstruction due to a congenital difference in size between the two breasts. The second group made decisions about breast reconstruction following a battle with cancer, and not all women with breast cancer chose breast reconstruction.

Summary of Evidence

Quantity of Research Available

A total of 591 citations were identified in the literature search. Following screening of titles and abstracts, 570 citations were excluded and 21 potentially relevant reports from the electronic search were retrieved for full-text review. No potentially relevant publications were retrieved from the grey literature search for full text review. Of these 21 potentially relevant articles, nine publications were excluded for various reasons, and 12 publications met the inclusion criteria and were included in this report. Appendix 1 presents the PRISMA³ flowchart of the study selection.

Summary of Study Characteristics

All 12 papers that were selected for review used qualitative methods. One study used qualitative and quantitative methods⁴ but only the qualitative data were included in this review.

Additional details regarding the characteristics of included publications and their participants are provided in Appendix 2 and 3.

Study Design and Data Collection

Twelve papers were included for final review. Four of these studies used a phenomenological approach,⁵⁻⁸ four used grounded theory⁹⁻¹² and the other studies did not specify the type of qualitative methods. All studies used interviews as their method of data collection.



Country of Origin

The country of origin for these studies is: Taiwan (n=1), France (n=1), United States (n=2), Germany (n=1) and United Kingdom (n=7).

Study Population

One study population was comprised of women with asymmetrical breasts who chose breast reconstruction (ten women).¹³ Eight studies (nine papers) explored experiences of women with breast cancer and mastectomies who were considering or who had breast reconstructions (159 women in total).^{4-12,14,15} Among these studies, two of them also interviewed the male partner of the women (13 male partners).^{8,15} Two articles (drawn from the same study) also included some perspectives from 35 health professionals, comprised of eleven oncoplastic surgeons, eleven plastic surgeons, eleven clinical nurse specialists, and two clinical psychologists.^{9,10}

Interventions (and Comparators)

One study described the experience of breast reconstruction for women with asymmetrical breasts. ¹³ Eight studies (nine papers) described the experiences of women who had mastectomies due to breast cancer and described their experiences with breast reconstruction, or decision making regarding breast reconstruction. ^{4-7,9-12,14}

One study looked at the experience of couples' decision making for breast cancer reconstruction post mastectomy among heterosexual couples.¹⁵ One study looked at heterosexual couples' view of breast cancer surgery and its impact on body image and sexual intimacy.⁸ Two studies interviewed health care professionals about their views on the adequacy of information provided to women¹⁰ and access to care and provision of choice for women with breast cancer considering breast reconstruction.⁹

Summary of Critical Appraisal

Many of the papers did not present an explicit theoretical orientation. Because of this, some of the articles remain at the purely descriptive level of analysis. Experiences are described and lumped into conceptual categories, but no explanation is provided that relates these experiences to broader social forces such as social norms, medicalization and how these can vary by social location.

One study (two papers) reported using theoretical sampling.^{9,10} Theoretical sampling is a process whereby the analyst decides what data to collect next in order to test emerging theoretical ideas. Theoretical sampling can lead to richer, more developed theoretical understandings.

Often, the biases, orientations or pre-existing perspectives and of the authors were not discussed in the article. This is particularly pertinent in this set of research as some of the authors have positions in plastic surgery departments. Therefore, they have a professional interest in having more women choose reconstructive options. The result is that in their interpretation of findings, women who choose not to undergo breast reconstruction are viewed problematically (e.g. Fu et al¹⁴).

Additional details regarding the strengths and limitations of included publications are provided in Appendix 4.



Summary of Findings

Breast Reconstruction among Women with Asymmetrical Breasts

One study was identified that interviewed women who had breast reconstruction because their breasts were asymmetrical in size.¹³ In this study in the UK, 10 women were interviewed whose breast sizes differences varied between 1 and 3 cup sizes.

A common theme emerged in which these women felt that they were "deformed", "weird" "not normal" and "unfeminine". There also appeared to be behavioural consequences of breast asymmetry as these women reported difficulty finding suitable clothes, avoiding physical and social activities and fearing intimacy.

After undergoing the surgery, most women reported that it was an improvement compared to their previous breasts: "Loads better than what they were", "I am not 100% happy with the result but it is still a million times better than it was." Despite the view that the present situation was an improvement compared to their previous one, some women expressed disappointment that there was still some asymmetry: "even though the operation has been done, I am still not even and it does still get me down, because they still look different." Some women expressed the view that they had an expectation of "perfect' or the "same" breasts, even though they admitted that surgeons had warned them that the outcomes of surgery would constitute an improvement rather than "perfect". As one woman explained, "No, they [surgical team] were . . . you know, you are not going to have perfect, you are going to have different, still but you get this expectation in your head that they are going to be like amazing. But, they were quite clear that it wasn't going to be."

The women in the study generally reported improved self-confidence in terms of how they felt about their body post-surgery. Some women reported that they felt comfortable about showing their unclothed body and breasts to others. Some women also talked about how they went out more often than previously and they felt comfortable wearing fitted clothes. Most women described how their improved self-confidence had a positive influence on their relationship with their partners. Others who were not in a relationship described increased feelings of confidence and increased feelings of femininity that they thought would contribute to increased confidence with future partners. Women described that their self-confidence could improve some more and they expected that this would occur as they became accustomed to their new body. Women also described the need to change certain behaviours such as not going out and wearing baggy clothing.¹³

Another theme that emerged through the interviews was secrecy. Most women revealed that they had told only family and close friends that they had undergone surgery to correct breast asymmetry. One woman explained that she would rather that people assumed that she had a breast reconstruction because of illness, rather than asymmetrical breasts. Another woman revealed that she let her boyfriend assume that she had breast augmentation rather than breast reconstruction due to asymmetry. The motivation for keeping it secret perhaps relates to their feelings that having asymmetrical breasts makes them not normal.

"I don't know. I thought everyone would think I was weird. And it would be like, 'Oh she's got this and she's got that!' And I thought it would be gossip and everyone would pick on me, and I just thought I couldn't tell anyone. I was so embarrassed. I still don't talk to people about it now."¹³



Another possibility is that breast reconstruction due to asymmetry is not well-known, so that women who have reconstruction do not know how such a procedure would be perceived by others:

"I'm fine, absolutely fine, talk to people about it, well I don't tell them why I had it done, but I talk to people saying that I've had it done, so people know that I've had my boobs done but they don't know why, so I'm confident talking to people in that way about it. . . I think it's more common for people to have breast enlargements and it's getting more and more common, and girls are doing it a lot now . . . look at Jordan and things like that, so I'm quite happy to say to people, 'Yes, I've had my boobs done.' I don't care . . . I'd rather them think I was vain than know that I had that problem."

Breast cancer survivors with mastectomies: how women make decisions regarding breast reconstruction

Many themes emerged when women described whether or not they chose breast reconstruction after receiving a mastectomy. Women spoke about the meaning of their breast to themselves and to their sense of identity. They also described their views on: the alternatives to breast reconstruction, and on surgery for reconstruction. These perceptions and views were shaped by the cultural and social context of the women's lives. Their views were also influenced by information that women collected by speaking to their doctor, their partner, their family, other breast cancer survivors and by searching for information on the web.

The meaning of the breast to the person

Many women expressed the view that their breasts are linked with their sense of femininity. Therefore, the loss of one or both of their breasts threatened this aspect of their identity. 5,7,11,15

"And I think with breast cancer . . . you're kind of undermined as a woman... This cancer probably more than any other, strips away at your femininity because you lose your hair, you can lose your breasts, you can lose your ability to have children as well, all these things . . ."11

For many women, undergoing breast reconstruction was a motivation to maintain their sense of femininity and to feel attractive.^{7,11} One study respondent spoke about how immediate breast reconstruction served to retain her sense of femininity:

"Just to have it all done on the one day, and kinda to wake up and be, well, I felt that I was still very much ..., looked like a female. So, yeah psychologically for me, that was a huge thing that when I went to the hospital I looked very much the same as I did when I came home."

11

However, for other women, breasts were not viewed as central to sexual attractiveness:

"White women...they always get implants of some sort. They always want bigger breasts, cause the white male, that's what they look at...in the black community the butt is the centre of attraction. That's what attracts men ...they're not looking at your breasts." (age 28)¹²

Some women did not link their breasts to their femininity. Nor did all women emphasize their breasts in terms of appearance or the loss of their breasts in terms of emotional or psychological consequences.^{5,6,14} In their study of Asian immigrant women living in the



USA, and of young women in the UK who opted not to have reconstruction surgery, these women often viewed their breasts in functional terms and described the role that their breasts played in childrearing or in marriage:^{6,14}

"Before even if my husband wanted it, I'd make it for him and let him play, right? But now I'm old. I don't think my husband would want to play anymore. So, what will I make it for? What do I make it for? What do I need it for?" (56-year-old mastectomy patient, no Breast Reconstruction [BR])¹⁴

"For me, I don't think I need it [reconstruction] because I already have my children...." (50-year-old mastectomy patient, no BR)¹⁴

"[The breast] has "done its duty" [in terms of breastfeeding her daughter (no BR)]6

These women did not choose breast reconstruction. They perceived that their breasts had played a role in their past in terms of childrearing or as wife. When these roles were perceived to be fulfilled, they did not see the need for breasts. Or, they saw their natural breasts as having an important role in breastfeeding, but a role that could not be fulfilled by a breast implant.

Feeling normal

A prominent reason offered by participants who sought reconstruction was to "feel normal".^{7,11,12} This was related to the view that with a reconstructed breast, a woman could feel whole again, whereas without reconstructive surgery, something would be missing. As one woman commented "I felt more whole again...I don't know, it's really hard to explain...for so long you look down and feel terrible and then all or a sudden it's gone because of the fact that your boobs are back" (BR).¹¹ Feeling normal meant feeling normal when looking in the mirror,¹² feeling confident enough to take off one's clothes in front of a potential partner,⁷ and looking normal for one's children.¹²

However, other women disputed the view that breast reconstruction could restore normalcy so they rejected the procedure: "I know it's not going to be like a normal breast with no imperfections. If can't be perfect, I ain't worried about it." (No BR, Age 60). 12 Furthermore, for some breast cancer survivors, the loss of one or two breasts "served as a difficult yet positive reminder of their struggle against breast cancer: "I am alive... I am a breast cancer survivor and this reminds me of my struggle" (No BR). 12

The ethos of the natural body

Some women were keen to pursue options that were natural "everything natural"^{6,12} and they had an ethic of body acceptance. Sometimes this view was informed by the notion that the body is a gift from God.¹²

"I believe in pureness of the body...everything natural...Whatever God says, that's what is, that is where my heart it at" (African-American woman, No BR, age 54)¹²

This emphasis on pursuing natural options, led some women to reject any form of breast reconstruction:

"it looks like a breast but isn't a breast",

"What you've got on your chest is a numb piece of fat from your stomach" (no BR),6

"I thought they looked,it just did not look natural" (no BR).6



But for other women, their interest in natural options led them to reject breast implants in favour of autologous breast reconstruction:

"I don't believe in implants...I don't want anything foreign in my body that I don't need foreign... He's like, 'we can use your skin'. That made me want to do it" (BR, Age 26).¹²

The view of the prosthetic breast

Women's view of the prosthetic breast also played into the decisions about undergoing breast reconstruction surgery. Some women explained that their dissatisfaction with their prosthetic breasts prompted them to pursue breast reconstructive surgery. Negative comments about breast prostheses included the notion that it felt degrading to wear one, 11 as it could fall out quite easily 11 and it left women with limited clothing choices. 11 One woman noted that breast prostheses did not come in skin tones suitable for African American women. 12 Furthermore, the bras that are required for the prosthesis were only available in beige, black and white, a dismaying thought for women who were interested in fashion. 12 Additionally, there was frustration that breast reconstruction was covered by their medical insurance provider, as this was mandated by law in the United States, however, prosthetic costs were not covered by insurance. 12

Rejecting implants for real or perceived medical reasons, due to side effects, burden of extra surgery

Some women rejected implants because they were fearful of leakage or ruptures. ^{12,14} Or, they were concerned that an implant would interfere with the detection of cancer recurrence, despite receiving reassurances from their physician that this would not be the case. ¹² In addition, certain communities, such as the African American community may distrust the advice of the medical community for historical reasons:

"Being black... we don't trust the medical profession. We figure they use us as guinea pigs... look at what happened at Tuskegee." (No BR, age 59)¹²

Some women were also concerned about undergoing extra, elective surgery. The inconvenience of multiple operations was a deterrent for some women who chose to reject breast reconstruction. They were not willing to go through additional surgery and the possibility of more pain, and suffering ^{6,12,14} for an elective procedure that they viewed as cosmetic rather than essential to their survival or quality of life.^{6,14} This concern may be particularly pronounced among women who faced prior and concurrent illnesses.¹²

For some women, autologous reconstruction was viewed more favourably than implants because it does not involve foreign materials in the body. ¹² But for others, autologous reconstruction was viewed as less favourable because it involves greater time under anaesthesia, more extensive recovery time, and pain in multiple sites:

"When he explained everything to me, that they would be moving muscles and that would make the pain more in my behind, I thought, hmm, pain in the chest, pain in the butt all at the same time? ... I've seen others ... it looks okay, but nothing to write home about to go through all that pain." (No BR, Age 57)¹²

External influences: the medical team

Breast cancer patients explained that the options for breast reconstruction were described by the medical team^{6,7,12,15} often early after breast cancer diagnosis. Women noted how their decisions regarding breast reconstruction was influenced by the information that was provided to them. However, in retrospect many women were dismayed that they had that



they had (a) lacked high quality information about outcomes; and (b) were not fully informed of all options available to them. Furthermore, perhaps because of the increased availability of immediate reconstruction, some reported that they felt rushed into making decisions about reconstruction.^{9,10}

Limited information about outcomes

Some women explained that they had shaped their decisions on incomplete information and unrealistic expectations about the outcomes of reconstruction. Some women who received implants felt that the result was not as natural as they had hoped⁹;

"I thought it would be more of a natural look, more of a natural droop than it is...that's what I wasn't aware of" (age 50, immediate BR)

Others who received autologous reconstruction reported that they were not prepared for the side effects. For instance, some women who had latissimus dorsi reconstruction (in which muscles and fat from the back are used to construct a breast) reported that they were not prepared for the axillary and back morbidity:9

"If it had been impressed on me that my back would be a problem then maybe I would have said 'right we'll go for a small implant and see how it goes." (aged 53, Immediate BR)⁹

Some women explained that they would have made a different decision had they had been fully informed. Some who opted for an implant would have chosen autologous reconstruction, and others who opted for implants stating that they would have chosen autologous reconstruction if that had received more information prior to making their decision.^{9,10}

Limited options

Some women felt that they were not fully informed of all the possible alternatives prior to breast reconstruction surgery.^{6,7,9,10} One woman explained her experiences:

"I would have liked to have explored a few more options... they seemed to try to steer you in a particular direction, and some of the information wasn't freely offered, it was only if you really pushed".⁷

Health professionals in the UK study also described situations where women are effectively denied choice about the type of breast reconstruction they receive:

'We do have three breast surgeons in the area who just basically they tell the patients what's going to happen to them. They all just get latissmus dorsis.. There's no real choice there is a hammer and there is a nail and that's all there is to it.' (Plastic Surgeon)⁹

Research conducted in France¹⁵ and the UK⁹ also suggests that the options that were presented to women seemed to vary with the medical centre where they were treated.^{9,15} For instance, if the medical centre did not offer immediate breast reconstruction (at the same time as the mastectomy), then reconstruction was discouraged by the medical team,⁹ or the option was not presented at all.¹⁵ Interviews with professionals reiterated the view that the type of reconstruction services that were offered could depend on local preferences and expertise.⁹ Professionals also expressed concern when referrals were made to centres with surgeons who were able to perform only limited repertoire of reconstructive services or



when women were not offered appropriate choice due to the local surgeon's desire to maintain ownership of the patient and their surgery.⁹

'I think we are short-changing women if they go to a unit in which they have a very limited repertoire. I think you have to be able to offer patients the full range because otherwise you're just short-changing them.' (Plastic Surgeon)

'We're doing far more autologous tissue reconstructions. It's not because necessarily our patients are automatically choosing that, it's because ...we have a particular bias, so there is a bias introduced, there's no question about that.' (Plastic Surgeon)

However, even when open choice was provided, patients and professionals described how women often opted for continuity of care with the same breast consultant and were reluctant to travel to distant centres.⁹

Personalized care, paternalistic care

Sometimes, the options that were presented to women were shaped by the notion of personalized care – that options should be pursued that are appropriate for the medical and physical state of the woman, such as size of the tumour, stage of disease etc.^{7,15}

"It depended on my biopsy during surgery, and I was told "well if the ganglions are not affected, it's ok, otherwise we will not go forward with the reconstruction" (age 59).¹⁵

However, sometimes, women felt that the surgeon provided recommendations to reconstruct the breast based on their emotional and psychological state:

"And that's why the surgeon understood...very kindly...that I was, psychologically, not able to accept the loss of my breast...Then he chose to give me an immediate reconstruction" (age 51).¹⁵

In another example, a woman explained that her surgeon recommended breast reconstruction because she was young, prompting the researcher to question whether the surgeon was imposing his own construction of femininity on to his patient.¹²

Compromised autonomy

Some women reported practices that suggest that their autonomy had been compromised. In a study in France, numerous women reported that breast reconstruction had been given to them in the form of a proposition rather than as a choice. ¹⁵ Four of the nine women in the study described this lack of choice:

"they (the medical staff) didn't ask for our opinion... To you (her husband) neither"

"the reconstruction.. that was not presented to us as a choice...it was a proposition which we should rather respect"

In other research studies, some women reported that they found out about surgical procedures to their body after it had occurred, 6,8 such as the surgeon leaving a flap on the body so that reconstruction would be easier to pursue in the future. 6

For women who opted not to have reconstructive breast surgery, they noted that breast reconstruction was promoted as the expected course of treatment:



"It's very much have the operation and have the reconstruction straight away and then deal with the consequences afterwards...when in fact it's not necessarily a step that needs to be taken"⁶

A number of authors have suggested that breast cancer reconstruction has become a normative process whereby the surgeon's notion of femininity has been imposed on the breast cancer survivor.^{6,12} For women who chose not to undergo reconstructive surgery, the experience of making the decision appeared to be anxiety provoking because they felt that their decision was not well supported by their medical team.⁶

Sourcing information from elsewhere

Many women explained that they did not rely exclusively on information from the medical team and they described the need to source information from elsewhere prior to making the decision about reconstruction, ^{6,7,9,10} This led some women to feel frustrated that this information had not been provided to them. ^{9,10} Additional information was typically gathered via the internet or by speaking to other breast cancer survivors. ⁷ Speaking to someone who had been through the experience of mastectomy and reconstruction was viewed as particularly welcome. ^{7,10}

Sometimes women turned to their families and consulted with community sources about treatment options. ¹⁴ Sometimes that meant that women could be making decisions on the basis of anecdotal evidence, or lack important information such as information about insurance coverage and breast reconstruction. ¹⁴ For immigrant communities, language barriers could mean that women have incomplete information about breast reconstruction options. ¹⁴ Sometimes family members could be uncommitted to the idea of breast reconstruction, due to the necessity of further major surgery. ¹¹

Women who had partners described the important role their partners played, as emotional and practical support.^{8,15} Some women highlighted that their partner played a consultative role and not decision making one, and this was very much appreciated by the women and viewed as respectful.¹⁵

Some women felt that there was a lack of information provided about life post-mastectomy without reconstruction. Most resources, both formal and informal, focused on reconstruction: "I wasn't given a sheet that said what it is like if you don't have one". Whereas photos of reconstructed breasts were easier to find, women found that it was difficult to see photos or to see women in the flesh who had received a mastectomy but who had not undergone breast reconstruction.

Breast cancer survivors with mastectomies: their views on their altered bodies post-reconstruction or without reconstruction

View of the altered body

Women who were pleased with the breast reconstruction emphasised that it "made them feel whole again" and that "it really feels like a part of you" whereas the prosthetic breast was viewed as something apart from it ("it's not really secure, it's not really part of you,") (BR). After breast reconstruction, these participants felt a greater freedom concerning their choice of clothing and were pleased that they were able to wear the same clothes that they wore prior to diagnosis and treatment. Women who were pleased with the reconstruction were pleased with the appearance of it. But some women were disappointed that their breasts did not resemble the photographs in the booklets that were



provided to them.⁷ Satisfaction with the outcome of breast reconstruction appeared to vary among participants.⁷ Generally, women who were satisfied with the outcome felt that it satisfied or exceeded expectations.⁷ Whereas those who were disappointed reported that the outcome was not as good as they had anticipated,^{7,8} or they had not been fully informed about all the options available to them:^{9,10}

"Different ways weren't discussed at all...so I just went along with it 'cause I thought that was the only thing you could have done. I did find out later that you could have the stomach muscles used etc. which I probably would have gone for...I would rather have had my own body parts rather than plastic" (immediate BR, age 50)¹⁰

This highlights the importance of providing women with realistic expectations and complete information.^{4,7,10}

Renegotiating sexual intimacy

Following mastectomy and breast reconstruction, women spoke about the need to renegotiate sexual intimacy.^{7,8,15} Women sometimes talked of wanting to cover up in front of their partners.^{8,15} Women were worried that their husbands might not find them attractive, while in interviews their partners asserted that they did indeed find their wives attractive, and as much as before the cancer had been diagnosed,^{8,15} Partners played a helpful role in supporting the women and asserting that they found them attractive.^{8,15} The process with women who did not undergo breast reconstruction was similar, and women generally reported feeling supported, understood and loved by their partners.⁵

Women with reconstructed breasts had to come to terms with their new body⁸ for instance a lack of sensation in their new breast,⁴ therefore this part of their body was no longer an object of pleasure.¹⁵ Some partners were fearful of touching their wives because of the pain that their wives experienced post-surgery.^{4,15} Some women reported that their sex drive was reduced during treatment and some months afterwards.¹⁵ However, the women reported that the troubles affecting their intimacy subsided over time as the couples adjusted to the new situation.¹⁵

Normal appearance

Women who underwent a mastectomy spoke about the need to maintain a normal appearance. For those who had received a breast reconstruction, they welcomed the freedom of wearing the same clothes that they wore prior to their diagnosis and treatment. Mothers were happy that they were able to wear the same swimsuit as before and they expressed relief that they were able to look the same for their children and protect their children from unwanted attention. To women who did not choose breast reconstruction, women emphasised other aspects of their femininity such as their slender figure and their beautiful face. Looking normal for women who did not choose breast reconstruction was also described, but this could require a bit more effort and required careful attention to prostheses and undergarments:

"Because I lost my left breast, I had to solve this problem. I have tried in many ways. I think underwear is a big problem. I spent lots of time choosing appropriate bras and finally I overcame this problem step by step."⁵

Return to normal life

Women who underwent mastectomy spoke about the need to return to their normal life as a means of restoring their sense of identity,⁵ such as their role in work family and



community.^{5,11} Women emphasized feeling a sense of self worth through working hard every day, having achievements at work, doing the best they can to look after their children and family.⁵ Although the loss of the breast was painful, they discovered a new sense of awareness in terms of health, in terms of the meaning of life and through the support of their family and community. Some women explained receiving breast reconstruction was helpful because when they received their new breasts, recurring thoughts about breast of cancer tended to subside and therefore it helped them to move on emotionally from the cancer experience.¹¹

Limitations

The populations that were studied are somewhat limited. No studies were found that described the experiences of breast reconstruction among the following groups: transwomen (those who are born as a biological male but identify as a female), women who had prophylactic mastectomies followed by breast reconstruction due to genetic markers of high breast cancer risk or among religious individuals where modesty is emphasised (e.g. Islamic). Further, no studies were found that described the experiences of women who were in lesbian relationships. It is quite possible that notions of identity, femininity, the breast and opinions about breast reconstruction might be different for these populations.

Although there was one article that described the experiences of women with asymmetrical breasts who chose breast reconstruction, there were no articles that were found that described the experiences of women who had breast reconstruction due to other types of breast abnormalities. Again, it is possible that notions of the breast and opinions about reconstruction could differ depending on the reason for the reconstructive surgery.

Some research described women's perspectives on implants as compared to autologous construction as compared to breast prostheses. However, no research was found that described how patients viewed differences between implant materials (e.g. saline vs silicone). It is unclear if there no literature was found because, to date, no researchers have undertaken such a specific inquiry, or whether in an environment of limited information sharing that women were not aware of the different implant materials available to them.

Two articles described the perspectives of health care professionals regarding the adequacy and the nature of information provided to patients before breast reconstruction. However, no articles were found that described the perspectives of health care professionals about their preferences, decision making strategies, or their views on side effects regarding type of breast reconstruction or type breast implant.

Finally, no studies were found in the Canadian context. It is possible that the way that medical professionals communicate with their patients might be different in the Canadian context.

Conclusions and Implications for Decision or Policy Making

Women who had breast reconstruction due to asymmetrical breasts described how their condition made them feel not normal and unfeminine. Post-surgery, women described increased feelings of self-confidence and that they were more comfortable wearing fitted clothes, going out and revealing their unclothed body to partners. However, some women were disappointed that the surgical outcome was not as good as they had anticipated. Women tended to be secretive about the reason for their breast reconstruction surgery.



Reasons for secrecy that were offered by the participants included not wanting to be viewed as "weird" and that the condition and its treatment are not well-known.

Many themes emerged when researchers explored how women with breast cancer, and then a mastectomy, make decisions about breast reconstruction. Importantly, this review highlights that decisions about breast cancer reconstruction are personal, value-laden and preference-sensitive. Women spoke about the meaning of their breasts to themselves and to their sense of identity. Notions of femininity, normalcy and the natural body varied amongst women and influenced their views on breast reconstruction. Women who opted to undergo breast reconstruction viewed their breasts as central to their notion of femininity. They found that breast reconstruction helped them to maintain a normal appearance. Women who had an ethos of the natural body chose not to have reconstruction or chose autologous reconstruction as they did not want anything foreign in their bodies. Implants may be favoured amongst women who did not want pain in multiple sites. These perceptions and views were shaped by the cultural and social context of the women's lives. Women's choices about breast reconstruction were also influenced by their views on the alternative (e.g. breast prostheses), their views on the surgical procedure and on the views of their community, family and medical team. Support should be offered for all breast reconstructive alternatives and including for those women who do not choose breast reconstruction.

This review also suggests that generally breast cancer survivors would like to be provided with complete information about the potential outcomes, and side effects, of all options post-mastectomy. Women often collected additional information about breast reconstruction by speaking to other breast cancer survivors and by searching for information on the web. Indeed, many breast cancer survivors included in the reviewed research welcomed having the opportunity to speak directly to breast cancer survivors who have undergone the type of procedure they were considering. Most often, medical teams raised the issue of breast reconstruction early in the course of treatment. Sometimes these options were framed by notions of personalized care. However, data from interviews with women and health care professionals in the UK and in France suggest that sometimes options were framed based on the expertise and availability of treatment options at the clinic and the perspective of the surgeon, rather than on the needs and perspective of the woman. Due to the finding that reconstruction options that are offered to women can be shaped according to the expertise of the breast surgeon, it may be beneficial to have post mastectomy options explained to women by someone other than the surgeon and who does not have a vested interest in surgical interventions. It is important that discussions cover all options including implants, as well as discussion of different types of implant material, autologous reconstruction, prosthetic devices, as well as no reconstruction. Availability of information in multiple languages will help address the needs of immigrant communities. Informed decision making and realistic expectations may contribute to greater satisfaction post-surgery.

Women who were pleased with their breast reconstruction emphasized that it enabled them to feel "whole" again and "normal" and gave them greater freedom in terms of clothing choices. Women who were satisfied with the outcome of surgery felt that it satisfied or exceeded expectations. Whereas those who were disappointed reported that the outcome was not as good as they had anticipated, 7.8 or they felt that that they had not been fully informed about all the options available to them: 9,10

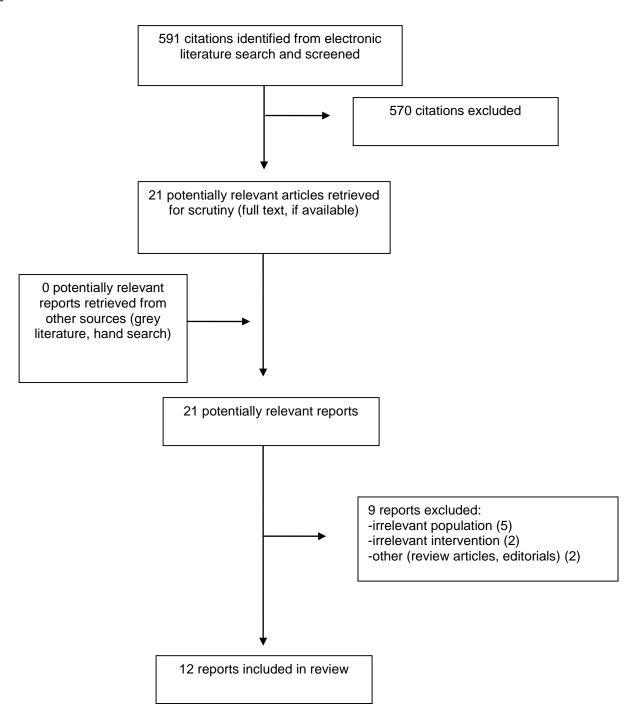


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Appendix 1: Selection of Included Studies





Appendix 2: Characteristics of Included Publications

Table 1: Characteristics of Included Studies

| First Author, Publication Year, Country | Study Design | Study Objectives | Sample Size | Inclusion Criteria | Data Collection |
|---|---|---|----------------------------|---|--|
| Chuang, 2018, ⁵ Southern Taiwan | Qualitative (phenomenological approach) | To understand the perception of body from women diagnosed with breast cancer more than 5 years previously and whose treatment included a mastectomy | 8 women | Women, Breast cancer, Mastectomy, dx of breast cancer> 5 years | 2-3 interviews lasting 90-120 minutes. |
| Fasse, 2017, 15 Bordeaux, France | Qualitative (design not otherwise specified) | To understand of couples' decision making for breast reconstruction | 18 individuals (9 couples) | >18 years old women, speaking and reading French fluently, being married and/or living together in a heterosexual long- term relationship since BC diagnosis. For those with BR, at least 6 months since completion. Exclusion: homosexual couples, double mastectomy, presence of learning disabilities or mental disorders, partners with a significant health problem. | Interview |
| Fu, 2017, ¹⁴ New York, USA | Qualitative (design not otherwise specified) | To investigate cultural factors, values, perceptions held by Asian immigrant women that might impact BR rates | 35 women | East Asian women, treated for breast cancer in the New York metropolitan area | Interviews |
| Schmidt, 2017, ⁴ Ragensburg, Germany | Survey and qualitative (design not otherwise specified) | 1. Are there differences between patients in their views on the importance of the breast | 20 women | Women who had mastectomy due to BC with (10 women) or without BR (10 women). Exclusion: | interviews |



Table 1: Characteristics of Included Studies

| First Author, Publication Year, Country | Study Design | Study Objectives | Sample Size | Inclusion Criteria | Data Collection |
|---|---|--|---------------------------|--|--------------------------|
| | | regarding femininity, attractiveness and sexuality that correlate with the decision for or against breast reconstruction after mastectomy? 2. How is the meaning of the breast related to a woman's self-concept? 3. Which impairments do cancer patients experience after breast surgery? 4. Are preoperative importance of the breast and postoperative esthetic satisfaction with the reconstructed breast related to one another? | | secondary breast reconstruction, medical complications, unfinished medical treatment, patients>75 years | |
| Holland, 2016, ⁶ England. | Qualitative (interpretive phenomenological analysis) | To understand the experiences of young women who chose not to reconstruct their breast(s) postmastectomy. | 6 women | Diagnosis of BC when < 50 years, at least 5 years post-dx, who opted no BR | Telephone interviews. |
| Loaring, 2015, ⁸ Midlands, UK. | Qualitative (Interpretive phenomenological analysis) | To understand couples' experiences of breast cancer surgery and its impact on body image and sexual intimacy | 8 individuals (4 couples) | Women with mastectomy with immediate reconstruction. Heterosexual couples (married or cohabiting) 18-65 years, in remission from BC, at least 6 months post-treatment, not receiving psychological treatment, understanding of | Interviews |



Table 1: Characteristics of Included Studies

| First Author, Publication Year, Country | Study Design | Study Objectives | Sample Size | Inclusion Criteria | Data Collection |
|---|---------------------------------------|---|---|---|-----------------|
| | | | | spoken English, sufficiently competent to give informed consent. | |
| Murray, 2015, ⁷ NW England | Qualitative (phenomenological) | To understand women's experiences of immediate BR following mastectomy, to better understand the factors influencing patient satisfaction | 9 women | Women with BC and immediate BR | Interviews |
| Potter, 2015, ¹⁰ SW England | Qualitative (grounded theory) | To explore patients' and health professionals' perceptions of the adequacy of the information provided for decision-making in BR | 35 health professionals (11 oncoplastic breast surgeons, 11 plastic surgeons, 11 clinical nurse specialists, 2 clinical psychologists 31 patients | Patients who had BR Health professionals who provide care to BC and BR patients | Interviews |
| NiMhurchadha, 2013, ¹³ UK | Qualitative (not otherwise specified) | To investigate the experience and outcome of undergoing corrective surgery for congenital breast asymmetry | 10 women | >age of 18 Undergone surgery for breast asymmetry at a specialist plastic and reconstructive surgery hospital in the UK. Fluent understanding of English. Surgery was in the previous year (July 2008–June 2009). | Interviews |
| Potter, 2013, ⁹ SW England | Qualitative (grounded theory) | To explore access to care and the provision of procedure choice to women seeking reconstructive surgery. | 35 health professionals (11 oncoplastic breast surgeons, 11 plastic surgeons, 11 clinical nurse specialists, 2 clinical psychologists 31 patients | Patients who had BR Health professionals who provide care to BC and BR patients | Interviews |



Table 1: Characteristics of Included Studies

| First Author, Publication Year, Country | Study Design | Study Objectives | Sample Size | Inclusion Criteria | Data Collection |
|---|----------------------------------|--|-------------|--|-----------------|
| McKean, 2013, ¹¹ UK. | Qualitative (grounded theory) | To understand the role of BR in women's selfimage. | 10 women | Women 18 years+ at the time of BC diagnosis who had BR following full or partial mastectomy. | Interviews |
| Rubin, 2013, ¹² New York, US | Qualitative (grounded theory) | To explore BR decision-making among African- American women | 27 women | Women who identify as African-American, 18+ years of age, who had undergone BC treatment since the implementation of the Women's Health and Cancer Rights Act. | Interviews |

BC = breast cancer; BR = breast reconstructive surgery; dx = diagnosis



Appendix 3: Characteristics of Study Participants

Table 2: Characteristics of Study Participants

| First Author, Publication Year, Country | Sample Size | Sex (% male) | Age range in years | Other relevant variable(s) |
|---|--|--|--|--|
| Chuang, 2018, ⁵ Southern Taiwan | 8 | 8 women | 41-59 years | Years after BC diagnosis: 7-11. 7 married 7 have children 5 with modified radical mastectomy, 2 with total simple and 1 with partial. 0 with BR |
| Fasse, 2017, ¹⁵ Bordeaux, France | 18 | 9 women + 9 male partners of the women | Women were aged between 33-66 years. Their partners between 40 and 76 years. | Duration of the relationship was 4-33 years. |
| Fu, 2017, ¹⁴ New York, USA | 35 | 35 women | 33-72 years | East Asian immigrant women Years living in the USA ranged from 3-40 years 17 with BR |
| Schmidt, 2017, ⁴ Ragensburg, Germany | 20 | 20 women | No BR median age=58.5 years BR median age=50.1 years | 10 women with BC and no BR 10 women with BC and immediate BR |
| Holland, 2016, ⁶ England | 6 | 6 women | 31-46 years | 4 married, 1 partner, 1 single. None were eligible for immediate reconstruction; all were candidates for delayed reconstruction but declined it. |
| Loaring, 2015, ⁸ Midlands, UK | 8 | 4 women + 4 male partners of women | 37-55 years | Participants were 37-55 years. 7 months-3 years post-surgery less than 4 years since BC diagnosis |
| Murray, 2015, ⁷ NW England | 9 | 9 women | 30-70 years. | 3-9 months post breast- reconstruction 6 married, 2 single, one with partner. |
| Potter, 2015, ¹⁰ SW England | 35 health care professionals 31 patients | 31 female patients Surgeons were 73% male Plastic surgeons were | Patients (31-72 years) | 35 health care professionals (11 breast surgeons, 11 plastic surgeons, 11 clinical |



| | | 82% male Clinical nurse specialist were 0% male Clinical psychologists were 0% male | | nurse specialists, 2 clinical psychologists). 31 BR Patients (26 married, 4 divorced and 1 single) |
|--|--|---|---------------------------------|---|
| NiMhurchadha, 2013, ¹³ UK | 10 | 10 females | 20-37 years | A year of less since their first surgery. Women with asymmetrical breasts with differences in breast sizes from 1-3 cup sizes 2 married, 2 with partner, 2 in long term relationships 4 single Procedures includes: tissue expander, implants, reduction surgery. |
| Potter, 2013, ⁹ SW England | 35 health care professionals 31 patients | 31 female patients Surgeons were 73% male Plastic surgeons were 82% male Clinical nurse specialist were 0% male Clinical psychologists were 0% male | Patients (31-72 years) | 35 health care professionals (11 breast surgeons, 11 plastic surgeons, 11 clinical nurse specialists, 2 clinical psychologists). 31 BR Patients (26 married, 4 divorced and 1 single) |
| McKean, 2013, ¹¹ UK | 10 | 10 women | 31-60 years | 7 Married, 1 divorced, 1 single, 1 partnered. Caucasian Less than 1 year-9 years since breast reconstruction |
| Rubin, 2013, ¹² USA | 27 | 27 women | 26-78 years (age at mastectomy) | 13 single, 10 married/partner, 3 widowed, 1 unknown All participants self- identified as African- American, some had BR some declined it. |

BC = breast cancer; BR = breast reconstruction



Appendix 4: Critical Appraisal of Included Publications

Table 3: Strengths and Limitations of Included Studies

| Strengths | Limitations |
|---|---|
| Chuan | g, 2018 ⁵ |
| -clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -explicit theoretical orientation is provided (phenomenological) -recruitment strategy was appropriate (though no theoretical sampling) -data collection strategy was appropriate -appropriate ethical standards were maintainedstatement of findings was clear -research is valuable. | -researcher sometimes conflated views of the participants, with their own perspectiveanalysis was of medium quality: would have liked some discussion of the differences among women (contradictive data) - no theoretical sampling |
| Fasse, | , 2017 ¹⁵ |
| -clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was good: researchers looked at inter-rater fidelity -statement of findings was clear -research is valuableresearchers were thoughtful about the limitations of their research. | -no explicit theoretical orientation is providedno theoretical sampling |
| Schmid | dt, 2017 ⁴ |
| -clear statement of the aims of the research -authors state that they used Interpretive phenomenological analysis -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintained. | Not enough detail provided regarding data analysis -statement of findings are weak -research results are weakno theoretical sampling |
| Fu, 2 | 2017 ¹⁴ |
| -clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful. | -no explicit theoretical orientation is provided - authors have appointments within plastic surgery departments at hospitals in the USA, yet they do not discuss how this professional role could influence their interpretation of the results that are provided from the patients. In particular, that they would be pro- reconstructive surgeryauthors are not explicit when they insert their own perspectives to their interpretation of findings (re: the patient's refusal of implants because of leakage or the patient's view that plastic surgery confers only cosmetic benefitsno theoretical sampling |



Table 3: Strengths and Limitations of Included Studies

| Strengths | Limitations | | | | |
|---|---|--|--|--|--|
| Holland, 2016 ⁶ | | | | | |
| -clear statement of the aims of the research -explicit theoretical orientation is provided (interpretive phenomenological analysis) -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful. | The relationship between the researcher and the participants is not well describedno theoretical sampling | | | | |
| Loaring | յ, 2015 ⁸ | | | | |
| -clear statement of the aims of the research -explicit theoretical orientation is provided (interpretive phenomenological analysis) -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful. | -no theoretical sampling | | | | |
| Murray | , 2015 ⁷ | | | | |
| -clear statement of the aims of the research -explicit theoretical orientation (phenomenological) -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful. | -no theoretical sampling | | | | |
| Potter, 2015 ¹⁰ | | | | | |
| -clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful theoretical sampling was used to identify professionals whose views were hypothesized to prove or disprove emergent theory | -no theoretical orientation is provided | | | | |
| NiMhurcha | dha, 2013 ¹³ | | | | |



Table 3: Strengths and Limitations of Included Studies

| Strengths | Limitations |
|---|---|
| clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately useful. | -no theoretical orientation is provided -no theoretical sampling |
| Potter | , 2013 ⁹ |
| -clear statement of the aims of the research -qualitative methodology and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is moderately usefultheoretical sampling was used to identify professionals whose views were hypothesized to prove or disprove emergent theory | -no theoretical orientation is provided |
| McKear | ı, 2013 ¹¹ |
| clear statement of the aims of the research -qualitative methodology (grounded theory) and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was moderate -statement of findings was clear -research is usefulresearch team discussed pre-existing assumptions -data were collected until saturation. | -no theoretical orientation is provided. |
| Rubin, | 2013 ¹² |
| -clear statement of the aims of the research Theoretical orientation is explicit (feminist) -qualitative methodology (grounded theory) and research design are appropriate for the aims of the research -recruitment strategy was appropriate -data collection strategy was appropriate -appropriate ethical standards were maintainedanalysis was strong -statement of findings was clear -research is usefulresearch team discussed pre-existing assumptions -data were collected until saturation. | - no theoretical sampling |