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Original article

Exploring novel dimensions of body experience after breast reconstruction

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ABSTRACT

Background: Studies on the post-breast reconstruction period are primarily conducted with questionnaires, focussing on general outcome parameters such as cosmetic result, quality of life or satisfaction. However, to explore how women see, appreciate and behave towards their own bodies, a different research approach is required. In this study, we used an empirical phenomenological design to explore how women experience their body after breast reconstruction in everyday practice.
Methods: A qualitative, descriptive phenomenological design was used. A total of 18 semi-structured in-depth interviews were conducted with women who had undergone implant-based breast reconstruction (IBBR, $n = 5$) and autologous breast reconstruction (ABR, $n = 13$). The interviews were tape-recorded, transcribed verbatim and subsequently coded and analysed using NVivo, a qualitative data analysis software program.
Results: A framework of six interrelated themes was identified: (1) 'the cosmetic body, (2) the sensed and touched body, (3) the body in action, (4) the sexual body, (5) awareness and (6) sense of self'. We found that women who have undergone IBBR report relatively similar changes in body experiences on all six themes, whereas women who have undergone ABR report a broad variety in changed body experiences after the reconstruction.
Conclusions: The six identified themes indicate that various dimensions of body experience are at play for women after undergoing breast reconstruction. Women with IBBR have more similar

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body experiences compared with women who have undergone ABR. This knowledge can be implemented in counselling before surgery and can support shared treatment decisions.

Introduction

Breast cancer is the most common form of cancer in women with an estimated 14,000 new cases in the Netherlands every year and a lifetime incidence of 12–13%.[1] The demand for breast reconstruction is increasing due to improved prognosis and survival,[2] among other things. In addition, due to medical–technological developments in testing for *BRCA*-1/*BRCA*-2 mutations, the number of prophylactic mastectomies, and hence the number of breast reconstructions, has also risen.[3,4] Breast reconstructions are noted to improve quality of life (QoL), body image and satisfaction rates.[5,6]

Most studies examining body-related impact of breast reconstruction are quantitative, focussing on outcomes such as risk of complications,[7–9] quality of life,[10–12] body image[5,13,14] and satisfaction.[15,16] Studies that investigate psychological well-being in breast reconstruction patients concentrate on parameters as depression and anxiety,[17,18] feeling of attractiveness[19,20] and sexual functioning.[21,22]

These kinds of studies show that it is difficult to formulate appropriate parameters or straightforward indicators of breast reconstruction outcomes. For example 'cosmetic outcome' can be objectified by the measurement of the symmetry of the breasts,[23] but sometimes subjective valuation by the doctor or patient herself is used.[10,12] 'Body image', one of the most commonly used parameters in QoL research, is also not a straightforward indicator, as it is used for assessing both physical intactness and the experience of actual physical traces after breast surgery.[24] Others also demonstrated that quantitative body image research is rigid, as it ignores the positive body-related experiences after breast surgery.[25] In addition, the relation between the cosmetic outcome, body image and QoL is not clear cut.[10,26]

To bypass the methodological problem of how satisfaction after a breast reconstruction should be quantitatively measured, we have chosen to conduct a qualitative research based upon in-depth interviews instead of questionnaires. Using a phenomenological approach and method, the primary aim of this qualitative study is to explore the different ways in which women experience their bodies after breast reconstruction in everyday life. Phenomenology investigates people's 'lived experience', for example, the way something is experienced from a person's perspective while taking into account that person's context, his or her lifeworld.[27] Unlike quantitative studies, which provide statistical general insights, our qualitative study gives rise to the classification of different patterns in body experience.[28] In this study, we have identified six different dimensions of bodily experience at stake after breast reconstruction. Our study, based upon a wide and heterogeneous sample, was not primarily designed to be representative and to compare different types of surgery. Yet, our findings suggest that there are some notable differences in body experience between autologous breast reconstruction (ABR) and implant-based breast reconstruction (IBBR) that warrant further investigation.

Methods

Study design

A qualitative, descriptive phenomenological method was used to identify a wide range of dimensions in how women experience their bodies after breast reconstruction. The results are based on 18 in-depth semi-structured interviews. We used the method of purposive sampling. The sample size adjusted based on the concept of 'saturation' or on the point at which no new information or themes are seen in the data.[29]

Participants

The participants were recruited from patients who had undergone breast reconstruction 3 years ago in a university medical centre in the Netherlands. Exclusion criteria were insufficient language proficiency, reoccurrence of breast cancer and major complications of the breast reconstruction (e.g., necrotizing flap or infection of the implant). Of the 131 operated women that year, we randomly approached 40 women by sending them an information letter with an invitation to participate. A total of 18 women (45%) responded and were telephoned to plan an interview. The mean age of the correspondents was 52.8 years (42–62); five women underwent an IBBR, 13 women an ABR (11 deep inferior epigastric perforators (DIEP), one transverse myocutaneous gracilis (TMG) and one latissimus dorsi flap) after prophylactic (four) or curative mastectomy (15). One woman first underwent a unilateral mastectomy and subsequently a contralateral prophylactic mastectomy with reconstruction of both sides. Table 1 shows the characteristics of the participants. Written informed consent was obtained from all participants.

Semi-structured interviews

A one-page topic list was developed from the literature on breast surgery outcome instruments and was used as a tool to guide the interviews. This topic list was reviewed and adjusted continuously during the course of the interviews (Appendix 1). The in-depth interviews were held either at the woman's home or in the outpatient department (OPD) of a plastic surgery department in the Netherlands. The interviews were tape-recorded, ranged in duration from 55 to 85 min and were performed by the first author. The participants were encouraged to speak freely about their experiences of their bodies. Additional questions such as 'What do you mean?', 'Could you tell me something more about that?' and 'Could you give me an example?' were asked to stimulate the participants.

Table 1
Patient characteristics.

	$N = 18$
Mean age at time of interview (years, min, max)	52.8 (42–62)
Partner at time of interview, yes: *n* (%)	16 (88.9)
Children at time of interview, yes: *n* (%)	17 (94.4)
Education, *n* (%)	
Low	11 (61.1)
Intermediate	5 (27.8)
High	2 (11.1)
Inherited predisposition for breast cancer, yes: *n* (%)	4 (22.2)
Radiation therapy, yes: *n* (%)	5 (27.8)
Chemotherapy, yes: *n* (%)	9 (50.0)
Timing of breast reconstruction, *n* (%)	
Immediate	15[d] (83.3)
Delayed	4[d] (22.2)
Type of reconstruction, *n* (%)	
Implant based	5 (27.8)
DIEP flap[a]	11 (61.1)
LD flap[b]	1 (5.6)
TMG flap[c]	1 (5.6)
Nipple reconstruction, yes: *n* (%)	
Nipple tattoo	8[e] (44.4)
Nipple-sparing surgery	10[e] (55.6)

[a] Deep inferior epigastric perforator.
[b] Latissimus dorsi.
[c] Transverse myocutaneous gracillis.
[d] One patient had initially an unilateral mastectomy and later contralateral prophylactic mastectomy with simultaneous reconstruction of both breasts.
[e] Unknown of one patient.

Analysis

The audio tapes were transcribed verbatim. To protect the respondents' anonymity, they were assigned a pseudonym. Their real names were only known to the interviewer (also the first author). To facilitate coding of transcript data and support the process of determining connections between codes that may suggest complex conceptual or theoretical models, the software program QRS-N*Vivo-9 was used.[30] The interviewer analysed the data by an inductive mean of coding, starting with descriptive open codes (e.g., showing breasts) followed by clustering of these codes into axial codes (e.g., sexuality), which subsequently led to the identification of general themes.[31] The coding process was constantly informed by the question of how these women experience their body after breast reconstruction and what meaning their bodies have.

Results

Six different themes were identified (Figure 1). These themes indicate six different meanings of one's body that are at stake after breast reconstruction (Table 2):

(1) The cosmetic body

Appearing 'normal' to outsiders is a recurrent issue for most women. Most of them were scared of the prospect of undergoing only amputation and not reconstruction. All women expressed strong opinions about different aesthetic aspects of their breasts and donor site: the shape, size, symmetry, scars, cleavage, nipples, position of breast and visible edges. Several women pointed out that the nipple makes a breast more complete and more real. The importance of the nipple recurs multiple times during this study.

Women with implants were generally content with the exterior of their breasts and one even considered the breasts more beautiful than before the reconstruction. The women who had undergone an ABR differed in how they valued the outside of their own body. Some were very content and described their reconstructed breasts as 'absolutely gorgeous', while others could not look at themselves in the mirror.

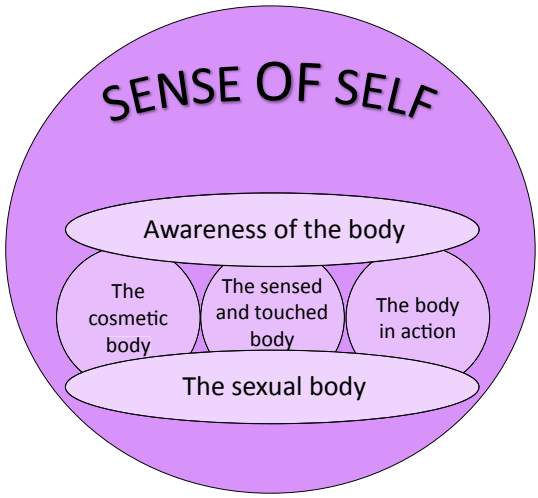

Figure 1. Framework of six interrelated themes of body experience after implant-based and autologous breast reconstruction.

Table 2
Illustrating quotes of the identified dimensions of body experience in women after breast reconstruction.

	Women with implant-based breast reconstruction	Women with autologous breast reconstruction
The cosmetic body	'I think it looks good … nice and round …. First it was more like this [flattens her breasts], so it's actually nicer now'. 'You get a normal cleavage again, can wear a normal shirt, can wear a bikini …. You feel normal again'.	'Gorgeously made, they look so splendid …'. (DIEP[a]) 'No, I don't like to look in the mirror, perhaps I should do it, but no …. I just do not look'. (DIEP) 'A breast without a nipple just isn't a breast I guess …'. (DIEP)
The sensed and touched body	'You feel something moving … just like something is shoving under the skin, very strange feeling'. 'Some parts have a numb feeling …. Here (points at her breast) I don't feel a thing, I can squeeze whatever I want'.	'Touching? No no, the belly-button not at all, and the tummy and breast preferably not as well. It's just doesn't feel pleasant …'. (DIEP) 'It [the reconstructed breast] adapts; If I'm warm, it warms up, if I'm cold, it gets cold …'. (DIEP) 'Some chunks, it's not completely equal. No it's not really bumpy but you feel some harder parts'. (DIEP)
The body in action	'With every movement you make you feel that thing getting in your way …. But there are only few things I can't do any more'. 'When you pay attention to it, you feel it with every movement but because it has been a while, it's just a part of me and that's fine actually'.	'And I do have strength but less in this arm than in the other one. So you use your body differently … I have to spread the daily activities, when it becomes too much it just starts irritating. And really gets thicker'. (LD[b]) 'And look I'm wearing trousers again, but there has been a long while that I couldn't do that. It putted too much pressure on the scar and that felt unpleasant'. (DIEP)
Awareness of the body	'With everything you do, although I say I don't have any limitations and I can do everything with it, it's something that I'm aware of all day long'.	'It looks good but it hurts, when you touch it, it hurts, so when I wash myself, it hurts. I get confronted with it every single day'. (DIEP) 'If you look when you just came out of the shower, then I am aware … I think, gosh how great. What a horrible time it was when I … you know, missed parts'. (DIEP)
The sexual body	'A sexual feeling I had in my breasts …. And whether I rub my arm or breasts now, it doesn't matter, it feels the same. It wasn't like that'. 'Normally the nipples play a major part in the sexual perception … and that's gone. So for me the feelings are just less intense'. 'You have to feel safe in your body, that has stood in my way for a long time …'.	'The feeling is less of course … but it belongs to me now, that's why I like him to touch them'. (DIEP) 'Because I don't feel it anyway and because that is awkward … it's just no use for me. So it's only the healthy side'. (DIEP)
The sense of self	'It is not mine, it not something belonging to me, literally, it can't be. It is something from outside the body. So it won't be'. 'You are and aren't complete. You are complete because you have a reconstructed breast, but you aren't complete because you miss your own two breasts'.	'Yeah, absolutely, they are completely my breasts … even though the sensation is less … I don't feel like I grab something that isn't real'. (DIEP) 'But I am really happy with it so you forget that afterwards. I feel complete again. And I wasn't …'. (DIEP) 'It's just a part of your tummy over there, right? …. And the edge, it's a different colour.… It's just strange, it's just a part of your tummy there (points at breast)'. (DIEP)

[a] DIEP: deep inferior epigastric perforator flap.
[b] LD: latissimus dorsi flap.

Women who underwent a DIEP flap reconstruction also reported the cosmetic impact of the abdominal surgery: They enjoyed the added benefit of a flatter abdomen, but they found that the resulting scar had disadvantages in both the visual and tactile aspects.

(2) The sensed and touched body

The variation in sensation of the reconstructed breast between the women in this study was vast. All five women with implants confirmed that sensation of touch decreased after the amputation. In contrast to the diminished sensation of the outer side of the body, the implants were constantly felt from inside the breasts, continuously reminding the women of the presence of implants.

Stronger negative experiences were expressed by a few women with an ABR, who continuously felt pain in the reconstructed breast. One respondent with an ABR reported that the pain increased when she touched the breast, which resulted in her not touching the breast herself or letting anyone else touch it.

As the operation area of an ABR was bigger than that of an IBBR, there was also a larger area where the sensation of touch was changed.

Although it is often claimed that implants may feel hard and cold, none of the women with ABR in our study reported a cold sensation. Instead, they claimed that the temperature of the breasts adapted to the body temperature.

In women who had undergone ABR, sometimes lumps of necrotic material were felt. In some cases, this was also visible and resulted in dimples on the breast. The lumps of tissue made the breast feel heavier than the normal breast.

Linking this to the resultant themes, the sexual sensation of the body was decreased due to the loss of sensation in the nipple and the tissue surrounding the nipple by the ablation. This shows that the sensation of the breast is not a separate theme in body experience; rather, it is closely connected to the other identified themes.

(3) The body in action

Limitations and necessary adjustments in routine activities caused by the breast reconstruction may affect how women experience their bodies and especially their breasts in daily life.

This theme was more prevalent in women who had undergone an ABR than in women who had undergone IBBR. Some women did not experience any limitation, but most women made remarks about small adjustments they had to make, although they were still able to carry out all activities. One respondent, for instance, left the groceries on the ground floor for her husband to take upstairs. If she would do that herself, the tension would increase in her axilla and cause pain.

The donor site can also present the need for adjustment in clothing. Due to the sensitivity of the scar and friction of clothes, three women reported adapting their underwear and clothing to the scars on their abdomens.

Women with implants scarcely spoke about limitations, but they admitted that they noticed the presence of the implants during many activities, because the implant was hard and did not move along with the motions of the arms. One woman experienced a clear restriction in bodily performance: She was not allowed to run anymore, as the movement of her upper arm along her IBBR caused abrasion of the skin, which could lead to infection surrounding the implant, according to the plastic surgeon.

(4) Awareness of the body

Generally, one does not have much awareness of healthy body parts.[32] Once body parts are impaired or arouse physical sensations, one suddenly becomes aware of those body parts. Being reminded of these body parts, in this example the reconstructed breasts, made the women aware of their oncological background or the presence of the *BRCA*-1/-2 genes. Women with implants were constantly aware of their reconstruction because they felt the implant's presence.

Within the group of women who had undergone an ABR, there was a huge difference in the awareness of the reconstruction. Some could be unaware of the reconstruction for hours; another

respondent, who continuously felt pain in her amputated and reconstructed breast, was aware of not only her breast but also its pervasive effect on all aspects of her life. This had an enormous negative impact on the overall satisfaction of the reconstruction.

Being aware of the reconstruction was not necessarily linked to a more negative body experience. Women with implants always felt the implants shoving inside their breasts, but they did not have a negative association with this feeling. Alternatively, few women with an ABR had a strong negative feeling towards their reconstruction because of the constant pain sensations and thus awareness.

The remarks of a woman who had undergone a TMG flap reconstruction are worth noting: During the ABR, some of her pubic hair was also transported to the site of breast reconstruction. It continues to grow on the reconstructed breast and needs to be shaved. A woman who had a DIEP flap reconstruction reported that she could recognize the skin on the reconstructed breast as her former skin from her abdomen. This meant that she did not really see her breast as breast, but only as a transported area of tissue placed on her chest.

(5) The sexual body

As one of the erogenous areas of the human body and responsible, in part, for sexual arousal, breasts play a major role in a woman's life and psychological health.[33] During the interviews, not only did the women speak of less tactile sensation in the skin but, more importantly, they also lost the sexual arousal around the nipples as a result of the amputation. Women who valued touching their natural nipples as a form of arousal and considered their nipples important erotic body parts during sexual interaction noted a greater change in sexual body experience after the breast surgery.

However, most women reported that early or abrupt onset of menopause caused by chemotherapy, hormone therapy or prophylactic oophorectomy affected their sex life much more than the amputation and reconstruction of their breasts.

The role of the partner was also acknowledged, for it is often through the explicit acceptance of the partner that these women were sexually active and could enjoy physical contact. Whether the breasts were involved during sex depended highly on the experience of pain while touching the breast. Some women reported fewer sexual encounters because they could not accept their breast cancer diagnosis and amputation. They did not feel comfortable in their own body and were not able to look in the mirror. Therefore, they underlined that they had not accepted their reconstructed breast yet. Whereas one woman said that she did not dare touch the scars of her breast and abdomen, and she did not want her partner to touch them, another said that she, in the course of time, regained a feeling of being safe in her own body, which enabled her to restore her sex life.

(6) Sense of self

Whereas an IBBR implies inserting a foreign object in one's body, an ABR implies inserting one's own tissue at another site. In both cases, this raises questions about whether this newly constructed body part is experienced as part of oneself.

All women with IBBR told us that although they were satisfied overall with the reconstruction, the implants were objects from outside the body, placed inside the body, so they would never feel natural and of oneself. For women with an ABR, it appeared to be different, because the reconstruction was made of their own tissue; it was easier to feel that the breast was natural and their own. Yet, although their own tissue was used for the reconstruction, not all woman felt the reconstructed breast to be their own.

As discussed in the first theme, most women in this study were afraid of an amputation, because they felt their body would not be complete anymore. It is interesting to note that a breast reconstruction can certainly add to an experience of being complete again; at the same time, this experience can also be rather ambiguous as expressed pertinently by one respondent: ‘you are and you aren't complete’.

Discussion

This study aimed to unravel further dimensions of body experience in women after breast reconstruction in daily practice. Six main themes that are interrelated and effect one another were

identified: the cosmetic body, the sensed and touched body, the body in action, the sexual body, awareness of oneself and the sense of self.

When comparing these dimensions of body experience between women who have undergone IBBR and ABR, it appears that women with IBBR have relatively similar body experiences. By contrast, women who have undergone ABR report a broad variety of experiences. No differences in body experience were observed between women with prophylactic or curative mastectomy in this study. Changes in bodily performances were mostly reported by women with ABR. These women were able to function normally although they bore the consequences later; that is, although their movements were not functionally limited, they often felt pain afterwards. By contrast, women with IBBR were more aware of the presence of the implant, but it had little impact on the capability of the body.

A recent quantitative, retrospective study compared QoL and patient satisfaction, assessed with the BREAST-Q, within women with ABR or IBBR.[34] Women with ABR displayed higher scores in psychosocial and sexual well-being and satisfaction with outcome, preoperative information and plastic surgeon when compared with women who had undergone IBBR. The authors conclude that for patients eligible for both ABR as IBBR, ABR is associated with higher levels of satisfaction and QoL. The study does not report on variety within the group of women with ABR or IBBR. Therefore, we cannot correlate our primary finding that women with ABR report a broader variety of body experience compared with IBBR to their conclusions. As reported outcomes of the BREAST-Q are predetermined and do not reflect any personal experience, there is no possibility to correct for personality as well as personal preferences. Thus, we believe that our study findings should not be compared with traditional questionnaires.

It is worth noting that the nipple holds significance for both types of reconstruction. Multiple women in this study stated that a reconstruction of the nipple—areola complex visually completes the breast, which is consistent with previous research.[35] Related to sexuality, many women experience their breasts as a zone of deep pleasure quite independent of intercourse, although sometimes not independent of an orgasm.[36] In this study, some women reported the tactile sensation of their original nipple as the beginning of sexual arousal. Losing this sensation by mastectomy has influenced their sexual experiences negatively.

The findings of this study can be implemented in preoperative counselling of breast cancer patients. This study underlines that multiple themes of body experiences should be addressed before breast reconstructive surgery. In addition, this study suggests that counselling before an ABR might be more difficult than counselling before an IBBR as the variety of body-related experiences is much more varied after ABR than after IBBR. This causes women to develop a more complete set of expectations of the different reconstruction techniques.

Limitations

All data were obtained post-operatively; therefore, we could not evaluate the changes in a woman's body experience due to breast reconstruction. In another parallel study, we explored women's experiences before and after a breast reconstruction, while applying a longitudinal design.[37] Our recruiting method could have potentially caused more positive body experiences to be reported, as non-respondents are often related to poorer post-operative outcomes.[38,39] However, within this group of participants, we did not observe a merely favourable outcome. In addition, note that only five respondents had an IBBR and 13 an ABR, resulting in an imbalanced inclusion. However, we do not believe that this biased our findings as our inclusion was led by the principle of 'saturation', implying that inclusion was completed the moment no new information emerged from the interviews.

Conclusion

In this phenomenological qualitative study, we found six themes that indicate various dimensions of body experience for women after breast reconstruction. It appears that women who have undergone an IBBR have more similar changes in body experiences after the reconstruction than those who have undergone an ABR. This knowledge can be implemented in counselling before surgery and can support shared treatment decisions.

Conflict of interest statement

None.

Ethical approval

The study was approved by the medical ethics committee of a university medical centre in the Netherlands.

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Appendix 1. Topic list with themes that were discussed during the semi-structured in-depth interviews of 18 women after breast reconstruction.

General information: full name, date of birth, place of birth, children, education and working life.
Medical history: breast cancer stage, presence of *BRCA* 1 or 2, family history of breast cancer, adjuvant therapies, type of reconstruction, nipple-sparing surgery, nipple reconstruction or tattoo and course of disease.
Preoperative themes: reasons for reconstruction; information-seeking behaviour; motive for chosen type of reconstruction; and the influence of partner, family, friends and medical team.
Perioperative themes: expectations of the breast reconstruction, for example, exterior, feeling or other thoughts, expectations of the surgery, preparations for surgery, unexpected events in hospital.
Post-operative themes: first sight of the reconstructed breast(s), partner's first sight of the reconstructed breast(s), satisfaction of surgeon, complication, reoperation and nipple reconstruction.
Body experiences after breast reconstruction: looking in the mirror, awareness of reconstruction, feeling own, complete, pain, itching, being naked, choosing clothing, showing breasts to others and presenting towards outer world.
Changes in body experience: personal opinion about relevance of breast pre- and post-operatively, changes in daily life, limitation in movement, vanity before reconstruction and now, intimacy with partner, arousal, desire, feeling attractive, influence of hormone changes, behaviour of the partner towards the breasts and experiences with buying and wearing lingerie.
Reflection: fulfilment of expectations, willingness to repeat procedure, acceptance, if you could do it all over.

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