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Medical Decision Making

An exploration of patient decision-making for autologous breast reconstructive surgery following a mastectomy

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ABSTRACT

Objective: The aim of this study was to examine patients' experiences of the decision to undergo breast reconstructive surgery following mastectomy.
Method: 21 Women, who had undergone reconstruction, took part in a semi-structured qualitative interview, which examined the participants' experience of the decision-making process. The recorded interviews were transcribed verbatim and analyzed using "framework analysis".
Results: Women who underwent immediate reconstruction spoke of the convenience of undergoing only one operation with regards to juggling work and childcare arrangements. For women who underwent delayed reconstructive surgery the reasons centre on dissatisfaction with wearing prosthesis. Others spoke of no choice, as immediate reconstruction was not offered as an option. However both groups did report similar influential factors and received and used similar informational content and informational sources in order to make their decision.
Conclusion: The study outlines the different motivations for undergoing immediate or delayed breast reconstruction and highlights that there is not always a choice offered to patients.
Practice implications: Future patients who are considering breast reconstruction should be provided with the relevant information to make a well informed decision and may benefit from different methods of information delivery that could include decision aids such as informational booklets, photographs, and videos.

1. Introduction

Breast cancer is the most common malignancy amongst women, affecting over 44,000 women in the UK alone [1]. The available treatment options for breast cancer depend on how advanced the cancer is and the preference of each individual patient. The mainstay is surgery, involving either mastectomy or breast conserving surgery. Women who have undergone a mastectomy may opt for breast reconstructive surgery or may choose to wear an external prosthesis. The aim of breast reconstruction is to restore symmetry, contour and breast positioning [2], while maintaining the maximum level of psychological wellbeing [3]. Reasons for undergoing breast reconstruction include restoration of body image and retaining a sense of femininity and wholeness [4,5].

Breast reconstruction may be in the form of prosthetic implants (e.g. silicone) or autologous tissue flaps, using the patient's own tissue. The choice depends on the suitability of the patient (e.g. enough excess tissue), the need for radiotherapy and patient preference. Some women prefer not to have prosthetic implants as it is perceived as a foreign object and because of possible complications such as capsular contracture [5,6]. The most common donor site for autologous tissue flaps is the lower abdomen as the deep inferior epigastric artery perforator flap (DIEP), considered to be the gold standard [7]. The DIEP flap uses skin and fat tissue without the rectus muscle/fascia from the lower abdomen to replace the mastectomy site. This removes excess tissue and fat from the abdomen resulting in a flatter stomach.

Some women choose to have the breast reconstruction as part of the same procedure as the mastectomy. This is referred to as immediate reconstruction. This approach may reduce the distress associated with loosing the breast following mastectomy and is associated with improved psychological and emotional wellbeing [8,9]. Furthermore, immediate reconstruction reduces the number of procedures required and is more cost-effective than delayed reconstruction [10]. However, coping with both a cancer diagnosis and reconstructive surgery within a short time-frame can be stressful [11]. Women who have undergone immediate breast reconstruction report greater work, social and daily activity

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disturbances as well as reduced vitality [12]. Delayed breast reconstruction is usually performed several months after the mastectomy, often following adjuvant therapy [13]. This delay allows the skin flap to settle and heal before breast reconstruction. Delayed breast reconstruction is advantageous for women who are overwhelmed by the cancer diagnosis [13].

Although breast reconstruction may be offered to reduce the adverse impact of mastectomy it is associated with negative psychological sequelae. Body image and beliefs about sexual attractiveness have been shown to be significantly worse in women who have mastectomy, compared to breast conserving surgery, regardless of whether they go on to have reconstructive surgery [14]. In addition, women who have undergone reconstruction have been shown to have poorer mood and lower wellbeing scores than those who have not undergone reconstruction [15]. Therefore it is apparent that decisions around breast reconstruction and the actual process are complex and associated with a range of psychological outcomes that may be influenced by beliefs about reconstruction and expectations of outcome.

Women faced with emotive health situations, such as decisions around reconstructive surgery, often accept decisions that are satisfactory rather than ideal and are likely to be influenced by the situation in which decision-making occurs [16]. Therefore, health care professionals are an important information source during the decision-making process [5,17]. Age differences in information preferences have been identified. Younger women (aged 50 and under) rated information related to physical and sexual attractiveness as important compared to older women (aged 70 and over) who rated information regarding self-care as more important [18]. Neill et al. [5] identified a need for further detail regarding the physical outcomes of breast reconstruction including loss of sensation and the recovery process following reconstructive surgery. The aim of this study was to explore women's decision-making regarding immediate or delayed autologous breast reconstructive surgery following mastectomy. The study focussed on reasons for undergoing reconstructive surgery, information sources and influential factors.

2. Methods

2.1. Participants

A convenience sample was identified via a patient database of two consultant plastic surgeons at a London teaching hospital. Patients were eligible to participate in the study if they had undergone autologous breast reconstructive surgery within the last 36 months, were over 18 years of age but were under 65 years and were English speaking. 30 women were identified to take part and approached. The sample was restricted to women that had received only autologous breast reconstructive surgery as there are specific issues related to being both the donor and the recipient of relocated tissue which are different from the issues around prosthetic implants.

2.2. Procedure

The study protocol was approved by the Local Research Ethics Committee. The Consultant in charge of the patient's care initiated postal contact with the patient. Participants were sent a letter inviting them to participate, along with an information sheet and consent form. Upon receipt of a signed consent form, participants were telephoned to arrange an interview time and date. Participants were asked for verbal consent to record the interview. The interviews were either conducted over the telephone or in a private room at the hospital, between January and November 2007. Interviews lasted between 25 and 80 min (mean 41 min). The interviews were conducted separately from routine treatment and were carried out by a researcher independent of the patient's care. There were no differences in the length of the interviews, or the depth of the responses, for telephone interviews compared with face to face interviews.

2.3. Interview schedule, data collection and data analysis

A semi-structured interview schedule was developed through research on previous studies and discussion with a plastic surgeon. This schedule was not rigidly adhered to, allowing discussion of issues that were important to the participants. Participants were encouraged to talk openly about their breast reconstruction, reasons for undergoing breast reconstruction and factors influencing their decision (including information).

All interviews were transcribed verbatim with accuracy checked against the recordings. A 'framework' analysis approach [19] was used which aimed to identify and organise data according to themes. Each framework is individual to each participant and allows dynamic movement between the levels of different concepts. The transcript of each participant's interview was carefully analysed, coded and grouped into emerging themes and sub-themes. Each participant's transcript was then reformatted into summary sheets and titled according to themes, using quotes to highlight them. Further conversion, grouped highlighted quotes of the same or similar themes from all of the participants, into one manageable cluster. This resulted in an organized hierarchical list of themes and sub-themes of all participants for both the immediate and delayed groups and a set of relevant extracts was selected to highlight each theme in Section 3. Each transcript was analysed independently by two researchers (SB and EAG). Only minor differences in researcher perspective emerged and these were resolved by mutual agreement.

3. Results

3.1. Sample characteristics

Twenty-three participants' responded (77% response rate). Two patients were not contactable leaving 21 patients who were interviewed. All participants had undergone either a Transverse Rectus Abdominis Myocutaneous (TRAM), Deep Inferior Epigastric Perforator (DIEP), Superficial Inferior Epigastric Perforator (SIEP) or Superior Gluteal Artery Perforator (SGAP) flap procedure at a London teaching hospital. Thirteen participants described themselves as Caucasian, 6 as black-African, 1 as black-Caribbean and 1 as white-Portuguese. The mean age of participants was 48 years (range 38–61 years). Sixty-one percent had obtained educational qualification of degree level or higher. Fifty-seven percent reported being married, 14% were divorced and 29% claimed to be single. The majority (85%) were working (14 full-time and 4 part-time). Twelve participants had undergone immediate reconstruction; the remainder had undergone delayed reconstruction. The mean time since breast reconstruction was 12.5 months (range 4–35 months).

3.2. Findings

The reasons why women chose to undergo breast reconstruction and the specific reasons offered by women who underwent immediate reconstruction and those who underwent delayed reconstruction will be presented here. Specific themes that emerged will be represented under the relevant sections. Two additional themes emerged which centred on the provision of information and the role of the surgeon in the decision-making process.

3.2.1. Reasons for breast reconstruction

The participants discussed their motivation for considering breast reconstruction. For many of the women this focussed around their emotional response to having a breast removed and their beliefs about how they would feel living without a reconstruction. The women spoke of the actual or expected effects of mastectomy on various aspects of functioning, emotions or attitudes. In particular, the women expressed body image concerns, including negative feelings towards their appearance and reduced self-confidence. Some women also spoke about not being able to cope with loosing a breast and how a reconstruction offered the opportunity to reduce the emotional impact around having a single breast.

> I knew somehow that it would be difficult for me to cope without a breast in terms of body image. . .. . .. I just felt that I could not live, to be flat chested on one side, so I think that was what made me go ahead with this. (P12. Age 43, immediate reconstruction)

Other women spoke of the importance of maintaining a positive body image and a coherent sense of their own identity. In particular, the reconstruction was viewed as a way to maintain femininity.

> I know that the human body it is supposed to be shaped that way, if you are a woman. . .. So a woman, an adult woman should have both breasts. (P10. Age 41, immediate reconstruction)

One woman spoke about how she viewed her breasts as part of her identity, implying that she might be perceived differently if she did not undergo a reconstruction.

> The fact that I've always had you know, big bust, it's almost kind of, its part of my character, but it's how people think of me. (P13. Age 40, immediate reconstruction)

The women also spoke of how a breast reconstruction would help to remove the reminders of cancer and so restore a sense of normality.

> You feel all the time you've got no breast there. Every time you take your bra off, it makes you think "I've got cancer". (P2. Age 54, delayed reconstruction)

> So it's just about feeling, just kind of more normal, I suppose, of feeling a bit normal straight away. (P11. Age 43, immediate reconstruction)

A further influential factor in the decision to undergo reconstructive surgery was that of health professionals, in particular the patient's surgeon, who supported the process. The surgeon's reputation and confidence in the outcome of the planned surgery was reported to be central to the woman's decision.

> I looked at on Mr X's website. Looked him up on that and you read it and it's all fantastically glowing. Yeah, he's got a practice in Harley Street. (P3. Age 46, delayed reconstruction)

For some women their trust of the healthcare team that would be overseeing their care was an essential component of the treatment process and served to reduce their anxiety about the procedure.

> I guess it made me more confident knowing that there was a good team who would be working on me. (P8. Age 52, immediate reconstruction)

Furthermore, it was apparent that the surgeon's authority and the patient's compliance with the surgeon's advice influenced the decision outcome.

> Mr X came in and umm, well I suppose its his whole authority, the way he spoke about it, you just. . ., I just went yeah, do it, do it now, it was just brilliant. (P3. Age 46, delayed reconstruction)

3.2.2. Reasons for immediate reconstruction

The main reasons for undergoing immediate reconstruction centred on practical issues (often to do with other commitments) and the personal costs involved with undergoing multiple operations. The majority of women who underwent an immediate breast reconstruction spoke of the opportunity for a single operation (mastectomy and reconstruction simultaneously) rather than undergoing separate procedures. For a number of women this centred on their ability to cope both emotionally and physically with multiple procedures.

> So I guess it was about whether I wanted to go through the pain and debilitation twice instead of the once. (P8. Age 52, immediate reconstruction)

> I have to recover after big surgery. . . takes a long time to recover and then go back and have another major surgery. (P12. Age 43, immediate reconstruction)

Other women spoke about the practicalities of undergoing two procedures rather than one and this impact of this on their everyday roles. For one woman this centred on work-related issues and the subsequent financial implications of taking time off work.

> I'm single I got a mortgage to pay and the considerations were practical more than anything. (P17. Age 41, immediate reconstruction)

For another woman the implications of taking time to undergo two procedures related to the practical difficulties of raising and providing care for young children.

> I have young children so I didn't want the choice of have two major surgeries; you know one after the other. (P12. Age 43, immediate reconstruction)

3.2.3. Reasons for delayed reconstruction

Reasons for undergoing delayed reconstruction seemed to centre around a lack of choice, namely that they were not a candidate for, or able to, undergo an immediate reconstruction. For these women immediate reconstruction was either not an option or was not offered to the women and therefore they did not have a choice regarding the timing of the reconstruction. However, the women were pragmatic in their discussion of this lack of choice and recognised that is was often due to the need for additional treatment or due to the limitations of the hospital. For some women the delay was necessitated by the need for additional treatments prior to undergoing reconstructive surgery.

> I needed radiotherapy and I think that they prefer you to wait until you've had the radiotherapy and then have the reconstruction. (P2. Age 54, delayed reconstruction)

For some women the hospital where they had their mastectomy did not provide reconstructive surgery and so additional arrangements for the reconstruction were necessary.

> It wasn't done at the hospital where I had my breast removed. I had to wait to come to X hospital to have the reconstruction. (P2. Age 54, delayed reconstruction)

It should be noted, however, that this apparent lack of choice was also spoken about by some women who under went an immediate reconstruction, although this was not so common. The

women in the immediate reconstruction group perceived that having the mastectomy and reconstruction simultaneously was a routine procedure at their hospital and therefore did not perceive that there was a clear choice to be made.

> It was as almost that 'women of your age kind of do this sort of thing' [have a reconstruction]. (P11. Age 43, immediate reconstruction)

Women who underwent a delayed reconstruction often spoke of their dissatisfaction with wearing a prosthesis and how this was a motivating factor in their decision to undergo reconstructive surgery. For some women the prostheses had been inconvenient and for others uncomfortable and was therefore something that they were pleased not to have to wear. Many women found the prosthesis impractical. Prostheses were seen to be either the wrong shape or size. This also affected the women's lifestyle by limiting the range of clothing available to them.

> You just felt that you could never wear clothes, you had to always be conscious and I just generally got fed up with it. (P6. Age 51, delayed reconstruction)

Not only did these women express how uncomfortable the prosthesis was but for some women it also affected their lifestyle and was a potential cause of anxiety and embarrassment. One woman reported a situation where the prosthesis fell out in public.

> I take aerobics classes and I can't compress it cause it's too heavy so I had to use the softies but there was a day in class when they fell out of my bra..... that was awful! (P20. Age 49, delayed reconstruction)

3.2.4. Provision of information regarding breast reconstruction

This theme encompassed the content and source of information that informed the women's decisions. Most women were provided with information about the different types of reconstruction, the outcomes of surgery and the recovery process. Information was gained primarily from the initial consultation with the plastic surgeon. There was a common theme expressed by the women that suggested they did not comprehend the information presented or that they chose to only concentrate on the positive aspects of the information presented to them. Where as some women wanted to know about the pros and cons of the different types of surgery, others expressed the need to avoid negative information, as it may have either altered their decision on the breast reconstruction or made them anxious and fearful of a procedure that already seemed daunting. These women consciously focused more so, on the positive side of the surgery and the 'successful' cases.

> Well I personally only wanted to hear about the successful ones (cases). I didn't really want to be told too much about umm, all the risk factors and all the drawbacks. (P19. Age 45, immediate reconstruction)

Furthermore the ability to absorb and comprehend the information provided was affected by the woman's emotional response to the need for additional surgery. Although all the women had received information few stated that they comprehended the information provided and in some cases were not concerned by this lack of comprehension. Among the delayed group some women spoke of a desire to "get it over with" and others spoke of a strong desire to have the reconstruction that they would have gone ahead with it "no matter what".

> It was quite a major operation, I think you know, I sort of turned a blind eye to it because I really wanted it done and everything, what they said to me went way over the top. (P2. Age 54, delayed reconstruction)

Some women suggested that they would have liked to have seen photographs of the surgeon's previous work during the plastic surgeon's consultation. In particular, there was an interest in the before and after photographs of breast reconstruction, as it was felt that this would help to build a realistic expectation of the outcome of the surgery. Of the women who had viewed photos reconstructions, many were impressed and inspired by the pictures. There was an expectation that the reconstruction would look similar to the photos they had seen and this was influential in their decision.

> They showed me pictures of a person who had it done ... you know and when I saw the picture, I was kind of; a bit impressed with it actually and umm, that swayed my mind to go ahead with it. (P21. Age 46, delayed reconstruction)

Some women did suggest that they would have liked to have more information with regards to the aftercare required. These women felt that they were not informed adequately about post-reconstruction care and did not feel adequately informed regarding their own self-care following the operation.

4. Discussion and conclusion

4.1. Discussion

This study examined patients' experiences of the decision to undergo breast reconstructive surgery following mastectomy. The study focused on reasons for the reconstruction, key factors that influenced decision-making and the information sources used to aid decision-making.

Different reasons for wanting breast reconstruction emerged between those who had undergone immediate reconstruction and those who had undergone a delayed procedure. For women who underwent immediate reconstruction common reasons for wanting a breast reconstruction were to avoid a period without a breast and as a consequence, to attempt to retain their body image and their perceptions of their own femininity. The findings confirm the importance of body integrity issues highlighted in an earlier study which found that 77% of patients expressed a need to feel whole again and 77% expressed a wish to regain their femininity [4]. In addition, women undergoing immediate reconstruction have expressed a belief that breast reconstruction offered the best option for avoiding the appearance issues associated with mastectomy and for retaining a positive sense of self-image [20]. As highlighted in previous publications the immediate reconstruction group reported that the opportunity to undergo a single procedure (mastectomy and reconstruction simultaneously) was a key factor in their decision to undergo reconstructive surgery [21]. Previous research has suggested that immediate reconstruction could allow the patient to avoid the psychological and emotional distress associated with loosing a breast [8,9,22]. In addition, there are financial advantages associated with immediate reconstruction both to the hospital and patient as immediate reconstruction avoids a second inpatient stay [10]. Khoo et al. [23] found the mean resource cost of delayed reconstruction was 62% higher than that of immediate reconstruction.

In contrast the women in our sample who underwent a delayed reconstruction expressed dissatisfaction associated with the external prosthesis; this had influenced their decision to undergo reconstructive surgery. This dissatisfaction centered on practical concerns associated with the prosthesis such as obtaining the right shape, size and fit. Some women reported that the prosthesis was uncomfortable, embarrassing and reduced confidence in daily activities. It was also reported to limit the range of clothing that could be worn due to the fear of exposing the prosthesis. Eighty-four

percent of the sample in Reaby's study [4] of breast reconstruction patients indicated that dissatisfaction with the prosthesis was a key factor in the decision to undergo reconstruction. In addition, for some women in our study, the prosthesis served as a reminder of the cancer, which they were keen to overcome. This is in line with previous findings that have reported that breast reconstruction may be viewed as a way of getting back to "normal" [5].

None of the participants in the delayed reconstruction group were offered an immediate reconstruction, either because they were not aware of the procedure, the hospital did not provide reconstruction or because they needed further adjuvant therapy. Although, delayed reconstruction has been found to be advantageous [24], the timing of adjuvant therapy remains a controversial issue, with recent research suggesting immediate reconstruction with radiotherapy being a safe procedure, demonstrating no significant adverse consequence over delayed reconstruction [25].

The key factor that influenced the decision to undergo reconstruction was the surgeon's reputation and experience. The women expressed confidence in the surgeon's ability to perform the procedure and a belief that the surgeon would ensure optimal results. The surgeon was perceived to be knowledgeable and experienced and therefore their advice was viewed as credible and appropriate. Previous research has shown that participants who chose reconstruction frequently reported that the surgeon's advice played a key role in their decision and that surgeons are an important informational source for women making a decision regarding this type of surgery [26].

The information given to women in this study focused on the different types of breast reconstructions available, details about the type of surgery, the pros and cons of the different types of reconstructions and the possible outcomes of the surgery both physically and aesthetically. The majority of participants retrospectively expressed a desire for more information; however a minority also commented that they were pleased that they had not been provided with a large volume of information as they might not have opted for reconstruction. Those women who expressed a preference for limited information may have been concerned that anticipatory regret would have prevented them from choosing reconstruction surgery. Anticipatory regret refers to the fact that the mere anticipation of post-behavioural feelings can influence people's behaviour, as behavioural choices have been found to be based upon anticipated emotional reactions following a particular behaviour [27]. As a consequence people attempt to avoid decisions that could result in regret.

Wolf's [28,29] qualitative study of women who had undergone reconstruction identified similar informational needs to the women in this study, as well as a need for information about the reconstructive procedure. Such information included the length of the process, cosmetic outcomes achievable, sensations of the reconstructed breast and donor site, recovery time, details of post-operative pain and discomfort and possible complications. Although information provision may result in improved outcomes following breast reconstruction surgery and may serve to reduce anxiety amongst some patients during their decision-making [30], it could have the opposite effect for other patients. This supports the assertion that information should be tailored to the individual needs of patients [14]. However, it is important to remember that patients' information needs are not static and can be influenced by a variety of factors [31]. Therefore it is important for health professionals to elicit the informational needs of women and tailor information provision accordingly. Novel methods of information delivery such as interactive digital education aid have been found to be beneficial in women considering breast reconstruction. Such methods may reduce anxiety and increase post-operative satisfaction by allowing women to accumulate information before seeing the plastic surgery consultant [30].

Women in this study found photographs were a helpful way to portray a realistic image of what the reconstruction could achieve, something also reported by Wolf [28]. This is in contrast to recent research which found that women felt poorly prepared for the outcomes of reconstructive surgery even when they had been shown photographs of reconstructions [32]. However pictures of other people's reconstructions may allow individual's to form unrealistic expectations, as physical differences between women and the type of reconstruction chosen may lead to different aesthetic outcomes. Differences include the level of scarring and the expected breast shape and size. The women in our study expressed a desire to see photographs of previous reconstructions performed by their surgeon.

5. Conclusion

The decision-making process to undergo breast reconstruction is both complex and emotional. This study has highlighted the important role of a credible information source and also the need for clear information about the outcomes of reconstructive surgery. The study suggests that there is a need for novel methods of presenting information to patients whether this is tailored information or photographs of previous reconstructions undertaken by the surgeon involved in their care. Although immediate reconstruction is associated with positive outcomes it is important to ensure that the informational needs of these women are elicited and the relevant and appropriate information is provided.

6. Practice implications

Implications of this study suggest that patients who are considering breast reconstruction should be provided with the relevant information to make a well informed decision. Many women expressed that there was a dearth of information focused on the surgical procedure and the required aftercare. However, while some women seek information, others avoid it and an individual woman, may vary in her information seeking behavior. Therefore it is important for health professionals to elicit the informational needs of women and tailor information provision accordingly. The current research highlighted that women may benefit from different methods of information delivery that could include decision aids such as informational booklets, photographs, and videos. The senior consultant has established a website explaining all options in breast reconstruction (http://www.didymafoundation.org). Further study is necessary to evaluate the usage of such a medium.

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