

Tracey L. Carr, PhD
Gary Groot, MD, PhD
David Cochran, BSc
Lorraine Holtslander, PhD, RN

Patient Information Needs and Breast Reconstruction After Mastectomy

A Qualitative Meta-Synthesis

KEY WORDS

Breast cancer
Delayed breast reconstruction
Immediate breast reconstruction
Information needs
Meta-synthesis
Qualitative

Background: Although many women benefit from breast reconstruction after mastectomy, several studies report women's dissatisfaction with the level of information they were provided with before reconstruction. **Objective:** The present meta-synthesis examines the qualitative literature that explores women's experiences of breast reconstruction after mastectomy and highlights women's healthcare information needs. **Methods:** After a comprehensive search of 6 electronic databases (CINAHL, Cochrane Library, EMBASE, MEDLINE, PsycINFO, and Scopus), we followed the methodology for synthesizing qualitative research. The search produced 423 studies, which were assessed against 5 inclusion criteria. A meta-synthesis methodology was used to analyze the data through taxonomic classification and constant targeted comparison. **Results:** Some 17 studies met the inclusion criteria, and findings from 16 studies were synthesized. The role of the healthcare practitioner is noted as a major influence on women's expectations, and in some instances, women did not feel adequately informed about the outcomes of surgery and the recovery process. In general, women's desire for normality and effective emotional coping shapes their information needs. **Conclusion:** The information needs of women are better understood after considering women's actual experiences with breast reconstruction. It is important to inform women of the immediate outcomes of reconstruction surgery and the recovery process. **Implications for Practice:** In an attempt to better address women's information needs, healthcare

Author Affiliations: Department of Community Health and Epidemiology (Drs Carr and Groot and Mr Cochran) and College of Nursing (Dr Holtslander), University of Saskatchewan, Saskatoon, Canada.

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Correspondence: Tracey L. Carr, PhD, Department of Community Health and Epidemiology, University of Saskatchewan, 107 Wiggins Rd, Saskatoon, SK, Canada S7N 5E5 (tracey.carr@usask.ca).

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practitioners should discover women's initial expectations of reconstruction as a starting point in the consultation. In addition, the research revealed the importance of the nurse navigator in terms of assisting women through the recovery process.

Mastectomy after breast cancer can negatively affect physical and psychosocial functioning.^{1,2} In response, some women elect to have breast reconstruction (BR). Breast reconstruction surgery takes the form of either immediate BR (IBR), which is initiated at the same time as the mastectomy, or delayed BR (DBR), which is performed at some point after mastectomy.³ Women's motives for either form of reconstruction are similar and include a desire to return to (or maintain) normality,⁴ to restore a sense of wholeness,⁵ and to avoid wearing a prosthesis.^{6,7} Furthermore, the return of the breast may mark a symbolic end of cancer treatment in the case of IBR or a literal end of treatment for those pursuing DBR. Ultimately, BR may allow women to move past the cancer experience and restore their physical and psychological selves.^{5,8,9}

The decision to opt for reconstruction and the timing of reconstruction are influenced by several factors. Women's decisions are influenced by general body image and sexual functioning concerns, in addition to a need to feel whole and restore femininity.^{6,10} The choice of IBR is often motivated by consideration of the impact a prosthesis would have on daily functioning. Some women are concerned about their ability to obtain a surgical appointment if they waited until after recovering from mastectomy and cancer.¹¹ Moreover, women who chose IBR rated interactions with their doctor more favorably than those who chose DBR.¹⁰ Many women who delayed reconstruction wanted to ensure that they had recovered from cancer before seeking reconstruction.¹¹ In addition, for some who did not initially consider reconstruction, their prosthesis struggle and body image concerns motivated an acceptance of reconstruction.⁶

Although women are generally satisfied with the outcome of BR,¹²⁻¹⁶ many encounter unanticipated struggles during the recovery period.¹⁷ Patients have expressed dissatisfaction with the physical result of surgery.¹⁷ Beyond this dissatisfaction, women struggle with adjusting to a new reality within their intimate relationships, revising a new conception of their femininity, and modifying their daily routine. These challenges are present whether the reconstruction is immediate or delayed.¹⁸⁻²⁰

The unexpected struggles of recovery from BR have caused women to question the accuracy of information provided by their plastic surgeon.¹⁵ Women felt ill-informed about their BR options, expressed regret about not knowing more about the recovery process,^{17,21} and felt that surgeons did not adequately inform them of postoperative realities.²¹⁻²³ Some women felt deceived by healthcare professionals who emphasized the potential psychological benefits of reconstruction without acknowledging the difficulty of the recovery.^{19,22,23}

Informing women about BR options while acknowledging both the risks and benefits is a complex process. The initial BR consultation typically occurs around the time of cancer diagnosis. Researchers have documented the negative impact a cancer diagnosis can have on a woman's ability to retain information.²⁴

Description of the complexities of BR treatment, combined with the fear experienced in the context of a diagnosis, can impair patient recall.²⁵ Accordingly, some researchers have suggested using audio recordings, written summaries, and one-to-one conversations to improve information exchange.²⁶⁻²⁸ If patients' information needs are better understood, the quality of provider-patient communication may also improve.²²

To better understand women's information needs, we performed a qualitative meta-synthesis on the relevant literature. A qualitative meta-synthesis involves integrating findings from several qualitative studies. This methodology seeks to clarify differences and highlight overlapping concepts and themes from multiple studies.²⁹ By using this approach, we can encompass the disparate experiences of women who have undergone BR. This approach is particularly useful when considering the differences between various women's access to information about BR, and it can provide insight into women's information needs.

To date, no meta-synthesis exists that explores women's experiences with BR. The primary objectives of this study were to explore the qualitative research regarding women's experiences with BR and to synthesize the findings in relation to women's information needs. A better understanding of women's information needs can translate into improved patient-centered care. A secondary objective was to determine whether women's information needs differ for those who choose IBR or DBR.

■ Methods

We used the methodology for qualitative meta-synthesis outlined by Sandelowski and Barroso.²⁹ This process was guided by a multidisciplinary clinical research team in consultation with a health sciences librarian. After a comprehensive search of the literature on women's experiences of BR surgery, the results were synthesized using a 3-stage process: (1) study appraisal, (2) study classification, and (3) synthesis of findings.

Search Method

For this review, we searched the following electronic databases and filtered results by the corresponding date ranges: CINAHL (1982 to May 2016), Cochrane Library (2008-2016), EMBASE (1980 to May 2016), MEDLINE (1950 to May 2016), PsycINFO (1985 to May 2016), and Scopus (2003 to May 2016). For the search, we generated key search terms and subject headings that encompassed breast cancer surgery, patient experience, and qualitative research. The specific search terms were "breast cancer," "breast reconstruction," "breast tumor," "mammoplasty," and "support groups," in addition to the MESH search terms of "breast neoplasms," "mastectomy," "breast implantation," and "psychology." The pilot search in MEDLINE rendered 28 titles.

The research team established the following inclusion and exclusion criteria to screen the results. Titles were included when (a) the focus was on women's experiences with the process and outcomes of breast cancer surgery, (b) 1 aspect of cancer treatment was BR surgery, (c) the impact of BR surgery was on different psychosocial aspects (body image, sexuality, relationships, satisfaction, etc), and (d) the study identified qualitative methods. Titles were excluded when (a) the focus was exclusively on other forms of breast cancer treatment (eg, mastectomy or radiography), (b) only the decision-making process leading to BR surgery (ie, preoperative experience) was considered, or (c) sources were non-English.

SEARCH OUTCOME

The online search of the 6 databases yielded 423 titles. After the duplicates were removed, 364 titles remained. The inclusion and exclusion criteria were applied by 2 independent reviewers. Agreement on the selection process was greater than 95%. The remaining titles underwent further review until a consensus was reached. For this review, we considered only those studies that examined patients' experiences with BR using qualitative methodology. When the screening criteria were applied to the abstracts, 348 titles were excluded and the remaining 17 were retrieved in full text (see PRISMA diagram in the Figure). Although no specific quality appraisal tool was applied to each article, we ensured that each study had a clear statement of aims, used a qualitative methodology appropriately, used a method of data collection that appropriately addressed the research question, and had a clear statement of findings.³⁰

Most studies were conducted in the United Kingdom (n=8). The other studies were conducted in the United States (n=3), Canada (n=2), Australia (n=2), Sweden (n=1), and Taiwan (n=1). A total of 258 female participants were included across the 17 studies. A total of 201 female participants from the studies underwent BR. Two studies included interviews with women's partners. A total of 16 partners were interviewed across two of the studies. In the process of data collection, we only included statements or researcher inferences from the women undergoing BR and not their partners. Furthermore, the women were interviewed separately from their partners. Considering the studies as a whole, 193 of the participants were interviewed one-on-one, whereas a single study³¹ used a focus group with 8 participants. For the synthesis, we focused on the women's experiences rather than their partners' perspectives. In Table 1, we outline the study method and objectives and the finding classification and rigor analysis of each study.

APPRAISING THE FINDINGS

We examined each study's methods and findings and evaluated the degree of analytical rigor. The evaluation was based on team discussions^{32,33} and an existing meta-synthesis study that used Sandelowski and Barroso's²⁹ meta-summary technique.³⁴ When considering a particular analysis, we noted the interview structure and whether an interview guide was used.^{32,33} We also noted whether the researchers verified their analysis with an outside source.³⁴ In addition, we assessed the studies to determine

whether the ratio of researcher interpretation to presented data was reasonable and well presented.^{32,33} This criterion evaluated whether the quantity of interview data presented was sufficient to support the authors' inferences. It also evaluated whether the inferences seemed reasonable in relation to the data presented.³³ We also used another set of criteria to ensure that the data were neither too specific nor too general.³² The summary of our observations is recorded in the Analysis Rigor column of Table 1.

CLASSIFYING THE FINDINGS

We used the criteria from Sandelowski and Barroso²⁹ to categorize each study's findings. Four categories of findings, ranging from least to most elaboration, are distinguished: topical survey, thematic survey, conceptual/thematic description, and interpretative explanation.²⁹ Topical surveys are removed from the meta-synthesis because of the survey's low level of elaboration.²⁹ One member of the research team categorized each study based on the degree to which the authors elaborated on the participant interviews. One study met this classification for low-level elaboration and was removed.³⁵ Of the remaining 16 studies, 12 were thematic surveys and four were classified as conceptual/thematic description. The classification process was verified by a second member of the research team.

The methodologies reported by the studies' authors were diverse: five were thematic analysis, and two were modified thematic analysis (thematic narrative analysis and phenomenological thematic analysis). In addition, there were 2 grounded theory studies, a qualitative feminist analysis, a hermeneutic phenomenology study, an interpretive phenomenological analysis, a framework analysis, an iterative coding study, and a study that used a heuristic approach. A description of the studies and their classifications is reported in Table 1.

SYNTHESIS OF FINDINGS

Following Sandelowski and Barroso's²⁹ methodological approach to synthesizing qualitative research findings, we performed a taxonomic analysis of the findings, which involved organizing individual concepts from the findings into a hierarchy. Following the authors'²⁹ methodology, when performing the taxonomic analysis, we focused on broadening the conceptual range over simply noting prevalent themes. After the taxonomic analysis, a constant targeted comparison was performed. Such a comparison contrasts different conceptual groups found during the taxonomic analysis. Contrasting the different conceptual groups reveals similarities and differences that clarify conceptual boundaries. Specifically, we contrasted the experiences of women who had undergone IBR with those who had undergone DBR.

COMPARING STUDY DEMOGRAPHICS AND METHODOLOGY

Reported participant demographic information varied from study to study. Table 2 details the demographic data extracted from each study. Although the precise form of demographic reporting varied, participant age, marital status, and type of surgical procedure are most frequently reported. Comparing the data presented in Tables 1 and 2, the studies differ noticeably in

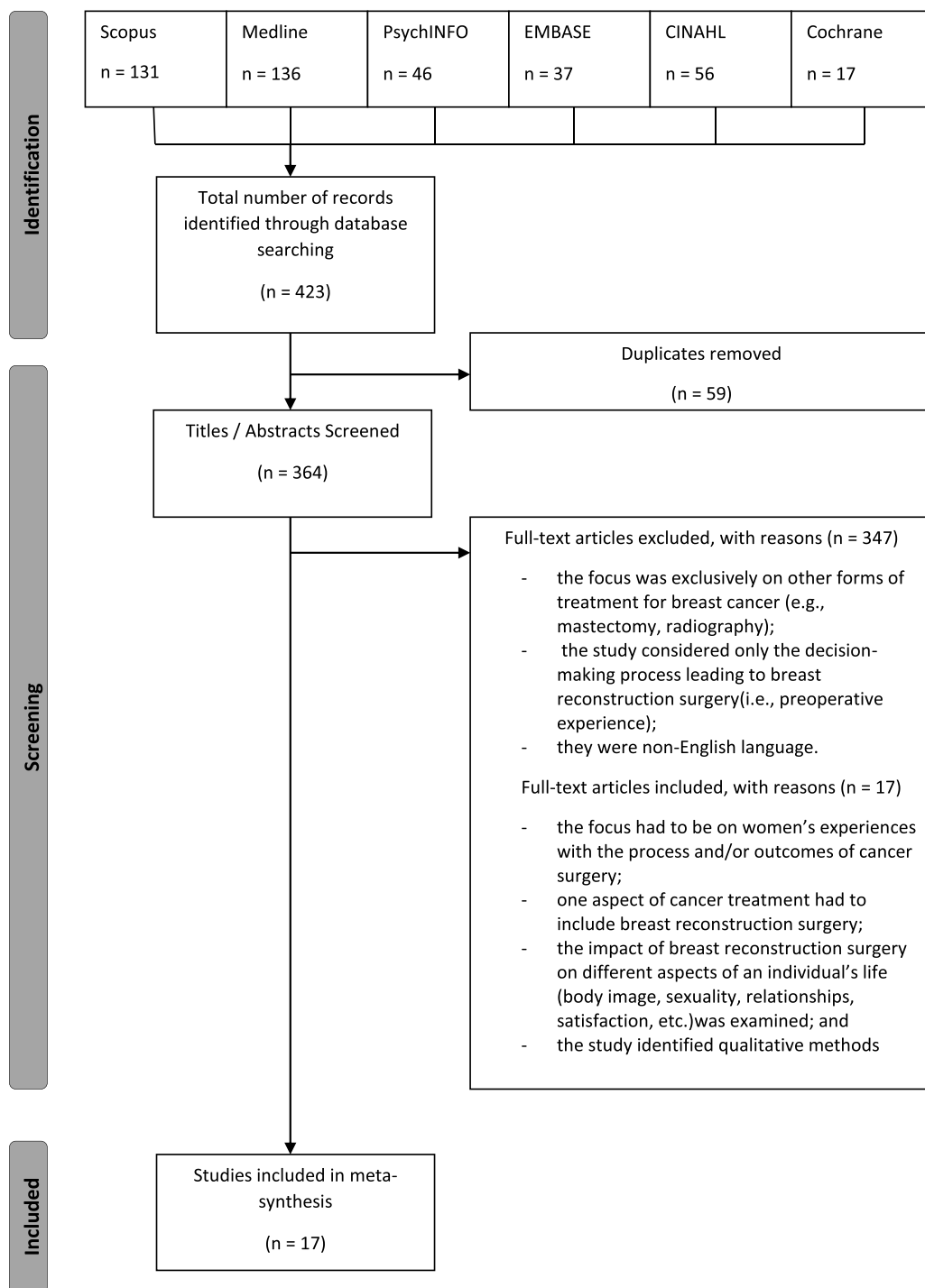


Figure ■ PRISMA diagram.


terms of both methodology and participants. Thus, performing a direct one-to-one association between studies may not produce meaningful comparisons.

Lack of methodological and demographic resemblance could be a concern in a meta-analytic study; however, Sandelowski and Barroso's meta-synthesis technique accommodates the varying individual study methodologies and demographics. The emphasis in a meta-synthesis is on the integration of results instead of comparison alone. Subsequently, the present analysis notes the similarities in women's information needs despite the diversity

or unknown demographics of participants. Although, by using Sandelowski and Barroso's methodology, we explored the similarities of women's experiences, we were also able to reveal the contrasting experiences of those who chose IBR over DBR.

■ Results

Our synthesis revealed the importance of the role played by the information provided by healthcare providers to patients

 **Table 1 • Study Attributes**

Authors	Objective	Methodology	Data Collection Method ^a	Analysis Rigor	Finding Classification
Abu-Nab and Grunfeld ³⁹ (2007) (England)	Investigate patient's perception of scaring as a result of breast reconstruction	Thematic analysis	Semistructured interviews; interviewed individually (N = 15)	The interview schedule was described by its general themes. Sample transcripts were verified by an independent researcher. The data were well presented.	Thematic survey
Crompvoets ¹⁹ (2006) (Australia)	Examine women's efforts to accept their changed body	Qualitative, feminist analysis	Interviews; interviewed individually (N = 4)	No interview guide and method of analysis verification was described. The data were presented well.	Conceptual/ thematic description
Denford et al ⁴¹ (2011) (United States)	Aim of study was to investigate women's conceptualization of normality	Thematic analysis	Semistructured interviews; interviewed individually (N = 35)	An interview schedule was described by its general themes. The initial themes were verified by a second researcher. The data were reasonably well presented.	Thematic survey
Fallbjörk et al ³⁶ (2012) (Sweden)	Examine women's breast reconstruction experiences	Thematic narrative analysis	Interviews; interviewed individually (N = 6)	An initial question was used to guide discussion. Consensus between the authors was reached regarding the products of analysis. Data were reasonably well presented.	Thematic survey
Fang et al ¹⁵ (2010) (Taiwan)	Examine women's breast reconstruction experiences	Hermeneutic phenomenology	Open-ended interviews; interviewed individually (N = 7)	The interview was guided by 5 prompt questions. Two participants reviewed the findings and provided feedback. Findings were well presented.	Thematic survey
Hill and White ¹⁴ (2008) (Australia)	Examine women's transverse rectus abdominis musculocutaneous flap breast reconstruction experiences	Thematic analysis	Semistructured interviews; interviewed individually (N = 10)	Researchers described the list of topics discussed in the interview. Participants verified the findings in a focus group setting. The findings were reasonably well presented.	Thematic survey
Kasper ¹² (1995) (United States)	Investigate how women manage social and psychological threats to themselves and how do they maintain or modify their female identity	Thematic analysis	Unstructured interview; interviewed individually (N = 16)	No interview guide was used; the researcher only had the participant freely express their experience. No method of verification was stated. Findings were reasonably well presented.	Conceptual/ thematic description
Loaring et al ⁴⁰ (2015) (United Kingdom)	Study examines couple's experience of breast reconstruction and how it affects body image and sexuality	Interpretative phenomenological analysis	Semistructured interviews; interviewed individually (N = 4) ^b	Interview schedule was used, and the broad themes were described. The third and fourth authors reviewed the late-stage analysis.	Conceptual/ thematic description
Marshall and Kiemle ¹³ (2005) (England)	Explore how breast reconstruction affects sexual intimacy and what coping strategies are used and identify what healthy support is needed	Grounded theory	Semistructured interviews; interviewed individually (N = 12) ^c	The topic areas were described, and the researchers provided some sample questions. The key themes uncovered were reviewed by participants. The presentation of results was acceptable.	Thematic survey

(continues)

 **Table 1 • Study Attributes, Continued**

Authors	Objective	Methodology	Data Collection Method ^a	Analysis Rigor	Finding Classification
McKean et al ¹⁶ (2013) (Scotland)	Using grounded theory, examine how breast reconstruction restores a perception of normality in terms of body image and a sense of self	Grounded theory	Semistructured interviews; interviewed individually (N = 10)	Example questions from the interview were provided. The participants verified the findings. The presentation of results was acceptable.	Thematic survey
Murray et al ³⁸ (2015) (England)	Explored women's immediate breast reconstruction experiences to understand what affects patient satisfaction	Thematic analysis, phenomenological approach	Semistructured interviews; interviewed individually (N = 9)	The topics of the interview questions were described. Participants provided feedback on the themes uncovered. The presentation of results was acceptable.	Thematic survey
Snell et al ³⁷ (2010) (England)	Explore women's preoperative experiences of breast reconstruction	Iterative coding	Open-ended interviews; interviewed individually (N = 28)	A copy of the interview guide was provided in the article. The method of analysis was somewhat vague. No method of verification was specified. The findings were well presented.	Thematic survey
Spector et al ²⁰ (2011) (Canada)	Explore women's expectations and information needs in relation to breast reconstruction	Thematic analysis	Semistructured interviews; interviewed individually (N = 21)	An interview guide was used, and some sample questions were provided. The results were verified by a qualitative research expert. The results were well presented.	Thematic survey
Spector et al ²² (2010) (Canada)	Explore women's experience of breast reconstruction recovery	Thematic analysis	Semistructured interviews and survey; interviewed individually (N = 20)	An interview guide was used, and some sample questions were provided. The results were verified by a qualitative research expert. The results were reasonably well presented.	Thematic survey
Truelsen ¹⁸ (2003) (Scotland)	Explore how mastectomy affected the decision to pursue breast reconstruction	Heuristic approach	Open-ended interviews; interviewed individually (N = 6)	Prompt questions were used to guide the interview. The analysis was verified by a counseling supervisor. The results were well presented.	Conceptual/ thematic description
Wolf ³¹ (2004) (England)	Examines women's information needs as it relates to breast reconstruction	Framework analysis	Focus group interviews (N = 8)	The interview guide was described as having prompts and memory aids to guide discussion. The analysis was verified by a breast care nurse. The results were reasonably well presented.	Thematic survey

^aThe N value refers to the number of women in the study who underwent breast reconstruction.

^bStudy also interviewed women's partners (N = 4); partner data were not included in the analysis.

^cStudy also interviewed women's partners (N = 12); partner data were not included in the analysis.

considering BR. The focus of this synthesis is on women's information needs as they relate to the most challenging aspect of BR: recovery from surgery. Although many women's experiences with the initial result of surgery and recovery were negative, many other women were very happy with their decision to have BR postrecovery.^{14–16,36} We grouped our findings regarding information needs into 2 main categories: expectations do not match

BR experience and assessing patient information needs. A summary of our key findings is provided in Table 3.

Expectations Do Not Match BR Experience

Women's information needs came from several sources. Although the specific route of referral varies by jurisdiction,

Table 2 • Study Participant Demographic Information

Authors	IBR/DBR	Age, y	Marital Status	Surgery type	Employment	Socioeconomic Status/Education/ Misc		Time between surgery and interview
						Ethnicity	Misc	
Abu-Nab and Grunfeld ³⁹ (2007) (England)	IBR, 8; DBR, 7	Mean, 50 (38–59)	73% Married	TRAM flap; all participants		14 white, 1 Afro-Caribbean	Mean, 13.6 mo (5–30 mo)	
Crompvoets ¹⁹ (2006) (Australia)	IBR, 0; DBR, 3; Mast, 1; IBR/DBR, 1	(33–53)		TRAM flap, 2; saline implant, 2				
Denford et al ⁴¹ (2011) (United States)	IBR, 32; DBR, 3	30–39 = 6; 40–49 = 16; 50+ = 13		TRAM flap, 12; tissue expander, 20; LD and tissue expander, 2; none, 1	Working, 23; homemaker, 5; unemployed, 2; retired, 3; no answer, 2	Black, 8; white Hispanic, 2; white/European American, 23; Asian, 2		
Fallbjörk et al ³⁶ (2012) (Sweden)	DBR, 6	Mean, 49 (39–61)	Married, 3; divorced, 1; common law, 1; widow, 1		75%–100% of full time	All Swedish		
Fang et al ¹⁵ (2010) (Taiwan)	IBR, 7	(36–52)	Married, 6; not married, 1	Autologous BR, 5; saline implant, 2				
Hill and White ¹⁴ (2008) (Australia)	IBR, 5; DBR, 5	Mean, 48.5 (39–59)	Married, 9; widowed, 1	TRAM flap, 10			Mean, 18.5 mo (10–31 mo)	
Kasper ¹² (1995) (United States)	BR, 16; mastectomy, 4; lumpectomy, 9	Mean, 47 (29–74)	Married, 15; divorced, 6; single, 3; widowed, 2; living with partner, 2			White		
Loaring et al ⁶⁰ (2015) (United Kingdom)	IBR, 4	(37–55) Women and spouses	All married	TRAM flap, 2; DIEP, 1; LD, 1		White		
Marshall and Kicmle ¹³ (2005) (England)	IBR, 11; DBR, 1	(38–58)	Married, 8; partnered, 2; unknown, 2	LD, 5; implant, 2; LD/implant, 2; rectus abdominis, 3		White British, 2; Asian British, 1; African British, 1	(7 mo to 3 y)	
McKean et al ¹⁶ (2013) (Scotland)	IBR, 6; DBR, 4	(31–60)	Married, 7; divorced, 1; partner, 1; single, 1	LD flap, 5; implant, 3; TRAM flap, 1; unknown, 1	Employed, 8; unemployed, 2	All white British	(<1 to 9 y)	
Murray et al ³⁸ (2015) (England)	IBR, 9	30–35 = 1; 40–45 = 3; 45–50 = 2; 50–55 = 1; 60–65 = 1; 65–70 = 1	Married, 6; single, 2; partnered, 1	Implant, 5; LD, 4			3.5–9 mo	
Snell et al ³⁷ (2010) (England)	IBR, 28	Average, 49		All implant				
Spector et al ²⁰ (2011) (Canada)	Unknown whether immediate or delayed BR	Mean, 52.9 (20–65)	~50% Married	Either implant or TRAM flap		85% white		
Spector et al ²² (2010) (Canada)	Unknown whether immediate or delayed BR	(20–65)	~50% Married			Living in Canada with Canadian health insurance		
Truelsen ¹⁸ (2003) (Scotland)	IBR, 4; DBR, 2; mastectomy, 2	(40–58)	Married, 7; divorced, 1		Work at shop, 2; shop manager, 1; factory worker, 1; office worker, 1; help at dance school, 1; community health worker, 1; sewing machinist, 1	85% white		
						Scottish, 7; Irish, 1		

(continues)

Table 2 • Study Participant Demographic Information, Continued

Authors	IBR/DBR	Age, y	Marital Status	Surgery type	Employment	Socioeconomic Status/Education/ Misc	Ethnicity	Time between surgery and interview
Wolff ¹ (2004) (England)	Unknown whether immediate or delayed BR	Mean, 51.5 (41–61)		Pedicled latissimus dorsi musculocutaneous flap, 5; tissue expansion, 2; free TRAM muscle flap, 1	Professional, 6; housewife, 2	Private healthcare, 3; NHS, 5; social class A: professional people, senior managers, 4; social class B: middle management executives, principal officers in local government, civil service, 4	All white	8.6 mo (4–14 mo)

Abbreviations: BR, breast reconstruction; DBR, delayed breast reconstruction; DIEP, deep inferior epigastric perforators; IBR, immediate breast reconstruction; LD, latissimus dorsi; NHS, National Health Service; TRAM, transverse rectus abdominis musculocutaneous.

the most significant information exchange occurs between the surgeon (plastic or breast) and the patient.^{15,19,37,38} When this information is lacking, women's expectations are inaccurate and they react with disappointment to the outcome of surgery and the reality of recovery. Women also relied on information from a surgical consultation and from the Internet, friends, and relatives.^{19,22} Yet, consultation with a plastic surgeon initiated the BR process. The surgeon discussed surgery options, informed the patient of the anticipated surgery outcome, and outlined any potential complications.^{15,19,22,31,37} Women were often presented with pictures of a reconstructed breast. The quality of the interaction with the surgeon varies from woman to woman. In some instances, the prospective patients were led to “[imagine] a ‘wonderful future’ in which their bodies would not be greatly altered after mastectomy.”¹⁵ In addition to receiving a surgical consultation, many women used the Internet to find other pictures and written descriptions of surgical outcomes.^{22,36–38} Such information played a role in shaping women's expectations of what their new breast would look and feel like. Women expected, based on their surgical consultation, to have their body return to normal or even improve.^{15,19,38} Unfortunately, when the information did not match the outcome of surgery and the process of recovery, women experienced disappointment.

INFORMATION CONFLICTS WITH OUTCOME

Despite women's expectations, in some cases, the surgery produced unanticipated outcomes. The unmet expectations could be grouped into 1 of 2 categories: the unexpected appearance of the breast or the unexpected feel of the breast.^{12,15,22,37–40} In the case of the aesthetic breast, some women expected their breast to more closely resemble photos they had seen during their surgical consultation, and others felt the breast looked unnatural.^{37–40} Referring to photos provided by a surgeon, a participant remarked: “There are photographs in the booklets they give you, but mine bears no resemblance to that at all.”³⁸ In a different study, a participant expressed similar dissatisfaction with photos: “I expected to look like that, like the photos of everyone else.”³⁹

Other women, in contrast, expressed dissatisfaction with the lack of a “natural” look for the breasts, and one woman exclaimed that “they really they look nothing like what I wanted and was used to looking like. So it was, it was very, very distressing.”⁴⁰ One research team noted the dissatisfaction of patients for whom the outcome failed to meet expectations.³⁷ Excessive scarring was described by researchers as a major component of dissatisfaction.^{22,36,37,39} One participant described her experience with scarring: “I expected to have one scar and I accepted that. I can't accept the other ones because they shouldn't be there.”³⁹

Other unexpected outcomes included the unnatural feeling of the breast and the limited movement of the breast.^{12,15,20,37,39} As 1 research team described, “Photographs conveyed little information about the sensation and texture of the reconstructed breast.”³⁹ One patient in a separate study expressed dissatisfaction with the “foreign” feeling of the breast: “I don't like

Table 3 • Key Findings

Key Findings	Source Article
Theme 1: Expectations do not match BR experience	
Primary information exchange between doctor and patient	15, 19, 37, 38
Internet, friends, and relatives as other sources of information	19, 22
Topics discussed in consultation	15, 19, 22, 31, 37
Information about surgical outcomes from the Internet	22
Expectation of normality or improvement after surgery	15, 19, 38
Subtheme: Information conflicts with outcome	
Unmet expectations: appearance and sensation	12, 15, 22, 37, 38, 39, 40
Perception that breast looked unnatural	37, 38, 39, 40
Unnatural feel and limited movement of the breast	12, 15, 20, 37, 39
Unexpected degree or location of pain	15, 22
Regret having surgery due to excessive pain or bodily changes	37, 39
Subtheme: Information inaccurately reflects process	
Unanticipated recovery period and difficulty adapting to changes	20, 31
Subtheme: Overwhelmed by information	
Struggle to retain information	31
Theme 2: Assessing patient information needs	
Concerns that motivate breast reconstruction	12, 15, 41
Desire to achieve the same look as before surgery	12, 41
Consideration of emotional outcome of surgery	15, 38
Experience of mastectomy and motives for reconstructive surgery	12, 18, 19, 41
Emotional struggle of mastectomy	14, 16, 19
Subtheme: Need for greater patient-centered care	
Sense of being objectified by surgeon	40

the way it feels. It still feels like something that's been grafted onto my body. I wasn't prepared for it being quite so fake."¹² Participants described the breast as feeling "hard as a snowball."³⁶ Regarding the struggle of dealing with skin toughened by radiation treatments after surgery, 1 participant explained, "My radiated skin was too tough so it curved inwards into the ribs instead of outwards."³⁶ In a different study, a participant described her breast in the following way: "I just felt it was artificial."¹⁵

The lack of preoperative discussion about breast movement was discussed. One participant expressed, "I did expect them to be more—they do not move...so I guess I wouldn't have expected them to move more."³⁷ Other women described the discomfort associated with the foreign body sensation of the breast: "There is a constant feeling that there is something there that should not be there."³⁶ The foreign body sensation proved to be a reminder of the surgery: "I didn't expect to always think of it, to always be reminded of it and always have it in my mind. I thought it would just eventually feel like part of me. And it doesn't."³⁴

Participants were also surprised by the location and degree of pain. Some experienced unexpected pain under their arms and in their upper back. A participant described the aspects of recovery that interfered with day-to-day exercises: "...I felt it was tight and limited my stretches."¹⁵ In 1 instance, the pain was so excessive that the woman believed it to be a sign of an infection.²² One woman directly admonished her surgeon for failing to inform her of the potential extent of the pain.¹⁵

For some women, the outcome of surgery was so severe and unexpected that they regretted having the surgery. Such regrets were often the result of the perception of excessive damage to the

body and/or surgical complications.^{12,37,39} Some women felt that scarring was excessive. One woman described, "I've got a scar from hip to hip and a 6 inch scar down my back.... I've got scars everywhere...they are hideous."³⁷ The excessive scarring was perceived as permanent damage to the body: "When you're in the shower, you sort of think oh my god is this my body now? And you feel less than you were before because you are not perfect anymore—and you never will be.... I feel less confident and less attractive."³⁹ The damage to a woman's self-confidence proved to be an especially pernicious outcome.

INFORMATION INACCURATELY REFLECTS PROCESS

In addition to being surprised by the surgery outcomes, many patients were surprised by the process of recovery. Several women did not expect the length of recovery time, which in some cases included additional procedures and significant adjustment to their changed bodies.^{20,31} One patient described the recovery process as "not a quick fix but like doing a marathon."³¹ Different researchers emphasized that the process could take more than a year in some cases.^{14,16,20,31,39,40} Participants expressed frustration at the time required to return to normal. One patient explained, "It was months before I felt, you know, anywhere near normal and even then, you know, it still took a while for my body, for my skin to stretch too, because I was hunched over for a while."²⁰

OVERWHELMED BY INFORMATION

The success of informing BR patients about the process and outcome of surgery was affected by the patients' ability to

engage with the physicians and to retain information.³¹ One researcher explored patients' struggle to retain information about BR options during the surgical consult. A participant stated: "You see I must have read it at least twice at the time but I can't remember it at all."³¹ The researcher suggested that the inability to process information had nothing to do with the complexity of the information itself; instead, the emotional stress of the cancer diagnosis made it difficult for the patient to focus on the discussion.³¹

Assessing Patient Information Needs

The findings reveal that a patient's information needs are influenced by the individual woman's concerns and circumstances. These circumstances include whether a woman has IBR or DBR. For example, women who chose IBR might do so because they fear the outcome of mastectomy alone. Women were concerned about their ability to wear clothes properly, to maintain their self-confidence and femininity, and to avoid the burdens of prosthesis.^{12,15,38,41} In 1 study, women expressed concern about their ability to wear clothes in an orderly manner.¹⁵ One participant explained, "If you wear a bra, you may appear to be more tidy and demure, as though your clothes are more perfectly fitted."¹⁵

In other studies, participants were concerned about looking the same as they did before the surgery or like those in the pictures they were shown.^{12,37,39,41} One patient hoped to have "virtually the same look as I had before."⁴¹ A participant in a different study stated: "When I went in for the mastectomy, I knew I was definitely losing something, and when I went in for the reconstruction I was getting something back."¹² Although the concerns outlined here refer to having a mastectomy, they show that women have information needs that involve understanding how their clothes will fit postsurgery and they feel a need to look the same.

When they considered IBR, women contemplated the emotional ramifications of mastectomy in addition to the physical ones.^{15,38} One woman explained, "I just wondered whether I would lose my self-confidence if I lost my breast and will end up having problems in coping."¹⁵ Researchers found that women's motivations for undergoing IBR included the desire to feel "normal," "to maintain femininity," and to "feel attractive."³⁸ They suggested that the perception of feeling normal was tied to feeling comfortable in an intimate relationship.³⁸ Awareness of women's emotional concerns is an important feature of women's information needs in the context of BR.

The experiences of women who delayed their BR reveal some informational needs that differ from those of women who underwent IBR. For women who delayed BR, their motivations to undergo the surgery were colored by their experiences living with a mastectomy and struggling with a prosthesis. The decision was mainly driven by a desire to return to "normality" in looks, sexuality, and routines.^{12,18,19,41} One participant described wearing a prosthesis once and hating it; she also described her frustration over not being able to "just pull on clothes and just go."¹⁹ She described her postsurgery

daily dressing routine as "[getting] back to normal again, you know, just put on a bra without having to fiddle around with anything."¹⁹ Another participant in Cromptvoets's¹⁹ study described wanting to return to normality in the context of her sexuality; she described "losing" her sexuality and "[wanting] to make it whole again."¹⁹ A different study emphasized women's desire to return to their body's premastectomy state; 1 woman explained, "All I want is to look like I looked. I don't want to go bigger or smaller, I just want to look like me."⁴¹ There are some similarities between the experiences of women recovering from IBR and those recovering from DBR. However, women who underwent DBR have experienced the reality of the struggle with the mastectomy and prosthesis. Firsthand knowledge of such experiences may be valuable to women considering BR.

These findings suggest that women are not fully informed about the emotional struggles that accompany mastectomy. Many participants described how living without a breast brought emotional turmoil.^{12,14,16,18,19,41} One woman described her struggle with her self-image before having surgery: "I've never had a very good, my self-image isn't very good, but then after this happened [the mastectomy] I thought, 'well, you didn't have anything to complain about before.'"¹⁹ Other women expressed revulsion at the sight of their body: "I couldn't look at myself, I was absolutely disgusted, my body image was... Just disgust, absolute disgust in my whole body.... I couldn't look, it was just... horrible, and I never did look, except for that once, I stood and looked in the mirror and I could feel my stomach churning."¹⁶ One woman emphasized that her motivation for the surgery was based on being relatively young and wanting to live her life to the greatest extent possible.¹⁴

NEED FOR GREATER PATIENT-CENTERED CARE

Ultimately, paying closer attention to a patient's specific needs will yield better patient-centered care. When such care is neglected, the patient can feel alienated.^{15,19,40} In some instances, women pursuing BR felt as though the surgeon was treating them as a "canvas" on which to produce his/her "art."^{19,40} Researchers emphasized "the perceived artistry of the surgeons"³⁹ and suggested that "at times the doctor-patient relationship could almost be compared with that of artist and muse."⁴⁰ Greater focus on the needs of the individual patient would likely address these feelings of alienation.

■ Discussion

This meta-synthesis explored qualitative research on women's information needs in relation to BR. Our findings suggest that women undergoing BR surgery need clear and comprehensive information. Satisfying women's specific information needs may lead to improved patient outcomes. Some women were dissatisfied with the initial outcome of BR and distressed by the process of recovery. These negative experiences with initial outcomes and recovery seem to be, to some degree, the

result of insufficient information from healthcare professionals during consultation. In terms of outcome, some women were disappointed by the look or feel of their reconstructed breast. Several women were not prepared for how much pain they would experience because of the surgery, and others were shocked by the degree of scarring. Women were also surprised by the tissue's lack of flexibility and tendency to restrict movement and routine tasks. Some women perceive the new breast as a foreign object and a reminder of the disease. In some instances, an undesirable physical outcome had a negative impact on the woman's self-confidence.

Other women were alarmed by the difficult realities of the recovery process. Some did not anticipate the length of time the recovery process required, whereas others were surprised by the need for additional surgical procedures. The excessive length of the surgery ultimately delayed women's ability to return to a normal routine and to overcome the entire cancer experience. These findings are consistent with other research that notes that women feel unprepared to deal with the changes in their body and the emotional challenges of the recovery process.²¹ Furthermore, some women have expressed that they were dissatisfied with their surgeons for not providing more information about the recovery process before surgery.²¹

Despite methodological and population differences between the 16 studies, women's experience of BR, especially as it relates to their information needs, is quite similar. Although the studies took place in different countries, with participant samples who varied in terms of demographics, women experienced the pain of reconstruction and the struggle with recovery in similar ways. At the same time, understanding women's BR experience would be improved with research that explores women's experiences using comparable methodologies and investigates the influence of different demographic features.

The secondary purpose of this study was to determine whether women's information needs differed between those who had DBR and those who had IBR. This study's findings demonstrate that women have unique information needs in regard to their expectations of the surgery and preparation for recovery. Although women's experience of IBR and DBR is similar, the findings suggest that there are some unique features of each experience that reflect different information needs depending on the timing of the procedure. Specifically, women worried that, if they did not undergo immediate reconstruction, they would have difficulty wearing clothes properly, feel loss, struggle to cope with the loss, and face the challenge to maintain self-confidence.^{12,18,36}

In contrast to the anticipatory concerns of those who elected to have IBR, women whose reconstruction was delayed were motivated to have BR by their experiences living with a mastectomy and a prosthesis.⁴² The surgery signaled an opportunity to return to normality, both physically and in their daily routines. These women sought to regain their femininity and sexuality and to overcome depression. Other research has found that younger women elect to have BR more often than older women.⁶

In addition to revealing women's reactions to surgical outcomes, 1 study considered the influence of a woman's

emotional state as the result of a cancer diagnosis on the consultation process.³¹ The researchers of the study suggested that the shock of the cancer diagnosis caused women to be overwhelmed by the BR consultation process.³¹ This finding is likely relevant to understanding women's information needs but requires further investigation to distinguish the precise nature of how the cancer diagnosis affects the BR consultation. Presumably, if the surgical consultation takes place much later, as in the case of DBR, the emotional weight of the cancer diagnosis would have less of an impact on the patient's information needs.

When considering the contrast in experiences of women who had IBR compared with those who had DBR, many women's experiences of pain and adjustment were similar. However, the 2 groups of women generally differed in terms of their motivations for choosing reconstruction in 1 general respect. Women who chose IBR are, to some degree, anticipating what life would be like without a breast and attempt to avoid that hypothetical reality. Women who chose reconstruction after experiencing living with mastectomy are motivated by their day-to-day experiences. Furthermore, for some women who had DBR, IBR may not have been an option for economic reasons such as women whose healthcare system or insurance plan does not provide coverage for BR. However, women whose reconstruction decision was not impinged by economic factors could benefit from knowledge of another's experience of life without reconstruction when deciding between IBR and DBR.

Despite the need for further investigation, it is worth noting that the use of audio recordings during consultation was helpful in terms of increasing patient recall and allowed patients to review information at their own convenience. There also was evidence that audio recordings enhanced patient participation in future decision-making.^{28,36} Some participants also suggested that having a support person at the consultation to assist with the interaction helped ease the feeling of being overwhelmed.³¹

This study demonstrated that women's information needs are defined by women's dissatisfactory BR experiences. Many women experienced unexpected physical outcomes, a body image threat, in addition to a recovery period of unanticipated duration. The unexpected nature of these experiences points to a need for greater information from healthcare providers. These women felt they not properly informed about the typical realities of BR. Consideration of each individual patient in terms of their disease, life circumstances, and values is necessary when delineating their information needs.

To improve patient care at the time of consultation, these findings emphasize the importance of the surgeon's understanding of the patient's unique situation and motives. Loaring et al⁴⁰ commented on the feelings of objectification women experienced during the process. Specifically, women felt as though they were being treated as a living work of art who became a muse and canvas for the surgeon.⁴⁰ Other research has demonstrated that the surgeon's perception of the patient's needs can differ from the patient's perception of those same needs.^{43,44} Such disconnection from the patient's information needs is a significant barrier to effective patient care. If information needs are better assessed, women can be more engaged in

the process and develop realistic expectations; patient-centered care can be achieved, and the BR recovery process may be improved.

Limitations

This study is subject to some limitations. Because the meta-synthesis process integrates the interpretation of findings of different researchers, it relies heavily on the quality of the researchers' interpretations. Thus, the limitations of the meta-synthesis are affected by the characteristics of the original studies. Similarly, common speech is used to describe women's experience of BR. Without a standardized language to articulate women's experiences, contrast between similar experiences within and across studies lacks some precision. Many of the studies used a retrospective design. It is difficult to know to what degree the women's recollections of their past experiences reflected their status at that time. Finally, this meta-synthesis is affected by the realities of differing healthcare systems, which make it such that women's experiences of BR are based on unique procedural aspects.

Future Research

There are questions raised by the findings that require further elucidation, namely, whether the experience of the surgical consultation is different for those pursuing IBR compared with those pursuing DBR. It seems likely that the consultation for IBR would be affected to some degree by the recent cancer diagnosis, but this was not explicitly stated in the studies examined in this meta-synthesis. Further investigation into women's information needs as they relate to IBR versus DBR is required to address these distinctions.

Conclusion

When women's information needs are not met, their experience of BR does not match their expectations. The shock of the cancer diagnosis has the potential to impinge on the exchange of information during the BR consultation. Nevertheless, when properly informed, women are able to better navigate recovery from BR and to ultimately move on from their breast cancer experience. If women are made aware of other women's experiences with BR, both the challenges and the benefits, their own experience can be improved. Ultimately, a successful recovery from BR can mark the end of recovery from the cancer itself.

Practice Implications

The results of this study suggest that more needs to be done by healthcare providers to address women's information needs in the case of BR. The relationship between the patient and the nurse navigator is an important service in healthcare. Nurse navigators are often in contact with the patients

throughout the recovery process and can help women with the different challenges they face. Two studies in the meta-synthesis commented on the role of the nurse navigator. Wolf³¹ emphasized the importance of the nurse navigator in helping the patients through the psychological aspects of recovery. Furthermore, Murray et al³⁸ noted that women who had a supportive relationship with their nurse navigator tended to report a more positive perception of the recovery process than women who had a poor relationship. We suspect that greater awareness of patients' concerns and information needs has the potential to translate into better patient care.

Beyond the individual nurse providing care, the findings of this study suggest the need for system-wide modifications toward improving the quality and access to information for patients considering BR. Women recovering from BR have found support groups for emotional support and information resources, which are unique to women who have experienced BR.^{38,44} If the healthcare institution provided women with access to such resources during the decision-making stage, women would likely benefit from speaking directly with those who had been through the process. When able to make a more informed choice, women can have more realistic expectations and a more favorable experience of BR overall. Because BR can lead to positive patient outcomes, providing the best patient-centered information to women considering and undergoing this procedure is imperative.

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