

Quality of Life After Postmastectomy Breast Reconstruction

Mary J. Nissen, PhD, MPH, Karen K. Swenson, RN, MS, AOCN®, and Elizabeth A. Kind, MS, RN

Purpose/Objectives: To explore women's expectations about postmastectomy reconstruction and factors affecting their quality of life after reconstruction.

Design: Qualitative focus group study.

Setting: Integrated healthcare system in a midwestern suburban community.

Sample: 17 women who had undergone mastectomies with immediate reconstruction between 1.4 and 5 years previously and had participated in a study of women newly diagnosed with breast cancer.

Methods: An experienced focus group moderator conducted two focus group sessions. Comments from the sessions were audiotaped and transcribed verbatim. The sessions involved semistructured, open-ended questions about perceptions of preparation, experience, and satisfaction regarding postmastectomy reconstruction. Thematic content analysis began with open coding at the level of individual comments and proceeded through two levels of higher-order categorization.

Findings: Although women felt well informed about breast surgery, they wished they had been more informed about some issues. Ratings of satisfaction generally were high despite some concerns about cosmetic outcome and persistent anxiety about recurrence.

Conclusions: Reconstruction allows women to feel comfortable in clothing, but recovery can be difficult, and reconstruction does not neutralize the biggest emotional challenge of breast cancer: fear of recurrence.

Implications for Practice: Women appreciate thorough information to prepare them for reconstruction and recovery. For aspects of recovery in which substantial variation exists, the range of experiences should be provided.

The evolution of opinions about postmastectomy reconstruction has followed a course that seems to have been influenced as much by societal norms as by science. Until the late 1970s, a stigma was attached to reconstruction. Women who sought reconstruction often were considered a special and troubled subset of patients with breast cancer (Rowland, Holland, Chaglassian, & Kinne, 1993), and many male surgeons considered reconstruction merely vain (Goldwyn, 1987). After the dramatic changes in societal views of women's roles and sexuality during the 1960s and 1970s, opinions of reconstruction also began to change. In addition, more efforts were made to improve reconstructive techniques and document psychological benefits of reconstruction. The earlier question of why women would choose to have reconstruction was reversed, and people began to ask why women would choose not to have it (Handel, Silverstein,

Key Points . . .

- ▶ Women choose reconstruction for physical and emotional reasons.
- ▶ Women who had reconstruction felt well informed, but some aspects of recovery were more difficult than they had expected.
- ▶ Women believed that reconstruction helped them regain some sense of normalcy despite their concerns about breast symmetry and naturalness and their undiminished fear of recurrence.
- ▶ Current research indicates that reconstruction improves body image but not other aspects of quality of life.

Waisman, & Waisman, 1990; Schain, 1991). Some people believed that women who declined to have reconstruction at the time of mastectomy might have a martyr syndrome (Hart, 1996; Schain, Jacobs, & Wellisch, 1984) or be less assertive (Noone, Murphy, Spear, & Little, 1985).

As the number of women undergoing reconstructive surgery has increased, so have efforts to answer questions about who chooses it and what its psychosocial consequences might be. Women who seek reconstruction tend to be younger than women who do not, and some studies show that they are more likely to be white, well educated, affluent, and married or in a relationship (Rowland et al., 2000). The two groups, however, are difficult to distinguish psychologically before surgery (Rowland, Dioso, Holland, Chaglassian, & Kinne, 1995). According to several studies, body image and feelings of attractiveness generally are better with reconstruction (Dean, Chetty, & Forrest, 1983; Mock, 1993; Noone, Frazier, Hayward, & Skiles, 1982; Pusic et al., 1999; Stevens et al., 1984), but other aspects of quality of life (QOL) do not differ (Hart, Meyerowitz, Apolone, Mosconi, & Liberati, 1997; Mock; Reaby & Hort, 1995; Reaby, Hort, & Vandervord, 1994; Rowland et al., 2000; Wellisch et al., 1989).

Mary J. Nissen, PhD, MPH, is an epidemiologist in oncology research, Karen K. Swenson, RN, MS, AOCN®, is the manager of oncology research, and Elizabeth A. Kind, MS, RN, is the director of survey research in the Health Research Center, all at the Park Nicollet Institute in Minneapolis, MN. (Submitted October 2000. Accepted February 2, 2001.) This research was funded, in part, by the Park Nicollet Foundation.

Digital Object Identifier: 10.1188/02.ONF.547-553

Recent studies have reexamined the psychosocial effects of reconstruction and suggest that they are not uniformly benign or beneficial. Among women who had contralateral prophylactic mastectomy, those who also had reconstruction were significantly more likely to express regrets about the decision to undergo removal of the uninvolved breast than women who did not have reconstruction (Montgomery et al., 1999). A comparison of women who had undergone breast cancer surgery an average of 36 days previously showed that during the immediate postoperative period, women who had mastectomy with reconstruction had lower rates of sexual activity and fewer signs of sexual responsiveness than those who had lumpectomy or mastectomy alone (Yurek, Farrar, & Andersen, 2000). A retrospective assessment of psychosocial outcomes in a large group of women who had undergone breast cancer surgery between one and five years previously found that women who had lumpectomy, mastectomy alone, or mastectomy with reconstruction did not differ in health-related QOL, including fear of recurrence. The benefit of reconstructive surgery for body image, however, was less than expected from previous work. Furthermore, women who had reconstruction were more likely to report that breast cancer had a negative effect on their sex lives (Rowland et al., 2000). The lay press has established the acceptability of mastectomy without reconstruction (Ratner, 1999).

A recent prospective study compared and contrasted QOL for women who had lumpectomy, mastectomy alone, or mastectomy with reconstruction, obtaining QOL measures after diagnosis (baseline) and at 1, 3, 6, 12, 18, and 24 months after baseline (Nissen et al., 2001). After controlling for the baseline QOL score and other potential confounders, the study found that women who had reconstruction had significantly greater mood disturbance and significantly lower well-being after surgery than women who had mastectomy alone. These differences remained 18 months after surgery. The purpose of the current study was to explore possible reasons for this unexpected result. The researchers hoped to gain more insight into the experiences of women undergoing mastectomy with reconstruction, from their initial decision to have reconstruction to their ultimate satisfaction with it. The researchers targeted four areas of inquiry: preparation for and expectations about breast cancer surgery, QOL and adjustment following reconstruction, satisfaction with reconstruction, and advice for other women. They also sought women's opinions about the earlier finding of greater mood disturbance and lower well-being after reconstruction.

Methods

This was a qualitative, descriptive study using focus group methodology. Qualitative studies are useful in investigating social, emotional, and experiential phenomena in health care (Giacomini & Cook, 2000). Focus groups, which allow for interaction among participants, can provide particularly rich data on previously unexplored phenomena (Appleton, 1995; Krueger, 1998; Powell & Single, 1996).

Sample

All members of the focus groups had participated in a study that was designed to assess the effect of advanced practice nurses (APNs) on QOL and cost of care of women newly diagnosed with breast cancer (Nissen et al., 2001; Ritz et al., 2000). This prospective study was conducted at an integrated

healthcare system that includes a hospital and clinics in suburban areas of Minneapolis, MN. All women who were 21 years or older and were newly diagnosed with intraductal or invasive breast cancer were identified through the pathology department for potential participation. Participants in this primary study were randomly assigned to either a control group, which received standard medical care, or an intervention group, which received standard medical care plus APN care. The primary study followed 210 participants for two years. In a subsequent study, 47 new participants received standard care plus APN care and were followed for six months.

Of the 257 patients who were enrolled in the primary study or the subsequent study, 50 were treated with mastectomy and reconstruction. Focus group participants were recruited from this subset of 50 women. All 50 were sent a letter that invited them to participate in a focus group on surgical treatments for breast cancer and asked them to call the investigator if they could attend on either of two dates. Of the 22 women who called, the first 20 were scheduled to attend (10 in each group), and, of those, 17 attended (9 in the first group and 8 in the second).

Procedure

The study was approved by the Institutional Review Board of HealthSystem Minnesota. Each of the two focus group sessions lasted two hours. Upon arrival, participants signed an informed consent document and completed a short questionnaire on demographic variables, type of reconstructive surgery, and any problems or complications experienced after reconstruction. The list of potential problems was one used by Schain, Wellisch, Pasnau, and Landsverk (1985). Participants were asked to put a check mark next to any of the 10 problems listed that they experienced (e.g., wound infection in breast, hardening of reconstructed breast, loss of feeling in reconstructed breast). A light meal was served as participants were completing the forms.

The moderator (one of the investigators) was a nurse with extensive experience in conducting focus groups. She introduced herself and the purpose of the focus group: to hear the participants' ideas and experiences with breast reconstruction surgery. She described the guidelines for discussion (e.g., "There are no right and wrong answers; we hope to hear a wide variety of opinions.") and outlined the four themes of discussion. Using a semistructured format, the moderator initiated discussion of each topic with the following questions.

1. Who talked to you about reconstruction surgery, and what information did they provide?
2. How did reconstruction affect your adjustment to having breast cancer?
3. How would you rate your satisfaction with your reconstruction surgery?
4. What advice would you give to a friend who was just diagnosed with breast cancer?

At one point, the moderator briefly described the results of the earlier QOL study (Nissen et al., 2001) and asked the women's opinions of the findings. As discussion of each topic progressed, the moderator probed with follow-up questions about the topic and attempted to elicit comments from all participants. The discussion in the first focus group influenced some aspects of how the second group was conducted. For example, questions about the outcome of the previous QOL study were introduced earlier in the second session. The assistant moderator took field notes

of the sessions, recording things such as body language expressing agreement or disagreement with what others were saying. Both sessions were audiotaped. At the end of each session, each participant was thanked and given \$20.

Analysis

Audiotapes were transcribed verbatim, and the transcription was checked against the tapes for accuracy. To provide investigator triangulation, data analysis was conducted by two of the investigators. The first step involved open coding (Burnard, 1991) in which all comments were given a heading. The number and type of headings were unrestricted at that point. Examples of headings included “reason for reconstruction,” “lack of sensation in breast,” and “take someone to appointments.” In the second stage of analysis, headings were grouped into higher-order categories. For example, “reason for reconstruction” was included in “decision making,” and “lack of sensation” was included in “problems, complications, and side effects.” These categories then were grouped according to their relevance to five areas: preparation and expectations, QOL, satisfaction, advice, and reactions to the earlier study.

The process of data analysis, from open coding to higher-order categorization, was cyclical rather than linear. The appropriateness of the analysis at each level was assessed by returning to the previous level as well as to the transcription itself to ensure that all substantive information was represented. The process continued until further analysis yielded no new information (i.e., until saturation) (Giacomini & Cook, 2000).

The resulting outline of the content of discussion was mailed to two participants, one from each focus group, for their comments. They indicated that it seemed to be an accurate representation that covered all aspects of the discussion. Two APNs, who had worked as breast cancer nurse coordinators with the participants of this study, reviewed a summary of the study findings and considered it a balanced report.

Results

Sample

Table 1 shows demographic and disease characteristics of participants. All participants were Caucasian. Reconstruction was done at the time of mastectomy for all participants, and the procedure was bilateral for four of the women. Two women had their implant(s) removed because of dissatisfaction with the outcome. All but three women also had some form of nonsurgical treatment. Ten received standard medical care in the primary study; one received standard plus APN care in the primary study; six received standard plus APN care in the subsequent study.

All of the women participated in the discussion with a striking degree of willingness and candor. Although they spoke expansively about issues, they also showed a respect for the general outline of topics that the moderator presented and did not stray far from the topic at hand. The moderator asked broad, open-ended questions near the end of each session (e.g., “Are there other things you would like to bring up?”), but these elicited few additional comments.

Diagnosis and Decision Making: Information and Expectations

Physical and emotional concerns: Women chose reconstruction for physical and emotional reasons. On the physical

Table 1. Participant Characteristics

Variable	n
Education	
High school	1
Some college/vocational	7
College degree	8
Master’s degree or higher	1
Marital status^a	
Never married	2
Married	11
Widowed	1
Divorced/separated	3
Employment status	
Not employed outside the home	5
Employed full-time	12
Income	
\$31,000–\$50,999	3
\$51,000–\$70,999	2
\$71,000–\$90,999	7
\$91,000 or more	3
Not provided	2
Family history of breast cancer	
Yes	7
No	10
Method of detection	
Self	8
Clinical exam	2
Mammogram	6
Not provided	1
Extent of disease	
In situ	1
Localized	8
Regional	8
Type of reconstructive surgery	
Expander with implants	8
Transverse rectus abdominis myocutaneous flap	9
Chemotherapy	
Yes	11
No	6
Radiation therapy	
Yes	3
No	14
Hormone therapy	
Yes	9
No	8
Bone marrow transplant	
Yes	2
No	15
Ever attended breast cancer support group	
Yes	5
No	12
Current age (years)	
\bar{x} = 53	–
Range = 40–65	–
Time since diagnosis (months)	
\bar{x} = 37	–
Range = 17–60	–

^aMarital status of all participants was unchanged from time of diagnosis to time of focus group.

N = 17

side were desires to look good in clothing, including swimsuits, and concerns that being physically active and feeling comfortable in bras would be more difficult with breast prostheses. One woman welcomed the chance to have larger breasts and, for that reason, considered reconstruction an easy decision. On the emotional side, women spoke of their belief that, without reconstruction, their disfigurement would serve as a permanent reminder of their breast cancer. One quoted her plastic surgeon as saying, “If you don’t have [reconstruction], every time you look at yourself you are always reminded of [breast cancer].”

Finding out about reconstruction: This decision had an automatic quality for several women. For example, one woman said, “[The initial consultation with a plastic surgeon] was just one of the appointments after diagnosis. You go see the oncologist, you go see the plastic surgeon, and it was a given that I was going to do it.” Furthermore, when the moderator asked the second focus group whether any of them had considered not having reconstruction, none indicated that she had. One wondered aloud why any woman would choose not to have it and offered “fear of the surgery” as the only reason she could imagine.

Women obtained information about reconstruction from a variety of sources: plastic surgeons, videos or pictures seen in a plastic surgeon’s office, APNs or clinic nurses, books, the Internet, and breast cancer survivors. In general, women believed that a great deal of information was made available to them—“as much as you wanted”—and believed they were very well informed. In fact, some women indicated that they had more information than they wanted, especially at a time when “a lot of things are coming at you so fast.” This was particularly true for two women who searched the Internet for information on their own or with their husbands.

Areas of inadequate information: Despite feeling well informed about breast surgery, many of the women cited specific issues about which they wished they had had more information. Five women were not shown pictures of reconstructed breasts before their surgery and believed it would have been helpful to have seen pictures. One woman who eventually chose to have her implant removed wished that she had received more information about prostheses as an alternative to reconstructive surgery. She said it was “annoying that you have to know the right questions to ask, because that is the information you get.” The most common specific issues about which women felt they were inadequately prepared were drains and pain. For example, one woman said, “I didn’t have any idea how long [the drains] were going to be in, so I was shocked that it was taking so long.” About pain, another said, “I didn’t understand just how painful it was going to be.” Other specific issues about which some women wished they had received more information included lack of sensation in reconstructed breasts, the pulling sensation through the abdominal area following the transverse rectus abdominis myocutaneous (TRAM) flap procedure, the types of bras that would be comfortable, and the fact that nipples were excised. (One woman was surprised when her initial bandages were removed and she saw that her nipple had been removed.) Even as women cited these perceived gaps in their preparation, many of them qualified their statements, acknowledging the possibility that the information was presented but that they did not process it at the time.

Unmet expectations: Many of the comments represented unmet expectations about breast cancer surgery in the sense that the women did not expect some developments after surgery. Another area of unmet expectations involved forgetting about

breast cancer. As noted earlier, some women chose to undergo reconstruction because they believed it would make it easier to forget about breast cancer. One woman quoted her plastic surgeon as saying that his goal was that “in two years, you are going to forget that you had cancer.” Later in the group discussion, the woman observed, and others concurred, that “you never forget it.” However, these were not expectations held explicitly by the women before their surgery. When asked directly about their expectations regarding breast cancer surgery, the women’s responses were more tentative and vague. As one woman put it, “When you are diagnosed and then you are presented with options, it happens—for me, anyway—it happened rather quickly. And so, looking back, I don’t think I spent a lot of time thinking about what are my expectations for this surgery.”

Quality of Life After Surgery: Difficulties and Support

Physical difficulties: The women discussed many physical symptoms they experienced after surgery, including those listed in Table 2 and difficulties involving drains, pulling in the abdominal area, lying flat in bed, short hospital stays, the “hot room” used for TRAM patients, pain with tissue expansion, and returning to normal activities. Participants expressed a noticeable diversity of experience in each of these areas, however. For example, comments on pain ranged from “It was not painful” to “I really hurt for over two years.” Women were more reticent in discussing sexuality and body image, but several indicated that they felt feminine and liked the way they looked in clothes. A single woman who was 45 years old when she was diagnosed and who was treated with chemotherapy remembered thinking, “I am becoming invisible, because I felt unattractive. So, yeah, body image, loss of youth, lots of loss.”

Emotional adjustment: When discussing their reactions to the loss of their breasts, there was a sense of equanimity among several of the women (see Figure 1). In contrast, a woman who chose to have her implants removed said, “I thought I wouldn’t miss them at all. But I really do.”

Other aspects of breast cancer presented more emotional difficulty: learning of the diagnosis (one woman developed a transient transglobal amnesia shortly after diagnosis); leaving friends and family at the hospital just before going into surgery (“There is no turning back. And it’s so lonely.”); and losing hair (“To some degree, that whole process of losing my

Table 2. Problems Experienced After Breast Reconstruction

Problem	n
Loss of feeling in reconstructed breast	12
Hardening of reconstructed breast	7
Second reconstruction on original side to improve outcome	5
Severe pain	4
Limitation in arm movement	3
Wound infection in breast	2
Fluid collection in wound	2
Arm swelling (lymphedema)	2
Death of part of flap (if applicable)	1
Complications that required removal of prosthesis	0

N = 17

When I found out there was cancer in it, I really didn't want it. I never felt like I had lost something. I look at the scars as badges of honor. I never really had a huge attachment to my breasts. It was fat and tissue, and now I have different fat and tissue there.

Figure 1. Reactions to Loss of a Breast

hair was more traumatic than the reconstructive surgery.”). By far, the deepest emotional challenge was associated with the fear of recurrence. Beyond the belief that they never would forget about breast cancer, women expressed significant anxiety regarding recurrence (see Figure 2). Some women indicated that regular visits to their oncologists relieved this anxiety somewhat. For example, one said, “Of course nobody really wants to have chemotherapy, but while I was having it, they were taking care of my body, and when it stopped, you are glad it is done, but then nobody is doing anything to make sure it is not there or coming back. And as you go in for your three-month checks, there is always somebody checking on you. I would rather have somebody watch me.” Most women did not feel that the anxiety had changed over time, although one noted, “I look at my surgery and my reconstruction as being when I *had* cancer. I don't consider that I have it any more.”

Sources of support: In the face of these physical and emotional difficulties, women welcomed the support provided by their families, coworkers, church communities, and friends, as well as through prayer. A common feeling was that “you need all the help you can get.” This view was not unanimous, however. One woman chose to tell no one other than family members and some close friends about her diagnosis and treatment: “This is not something that I broadcast to the people I work with. I felt this was a personal thing.” In contrast, another said she sent out funny e-mails to 90 people. “That helped me, that helped my friends to deal with it, and it got me a lot of support.” Five women had attended breast cancer support groups.

The women talked about changes in relationships as a result of breast cancer, some for the better and others for the worse. Some were puzzled by the behavior of friends who seemed to become more distant. One woman hypothesized, “[The cancer diagnosis] brings up other people's feeling of not ever having had to face their own mortality. I think that some people think they are going to live forever. You really face down death, and a lot of people haven't been there yet, so they can't relate.”

Satisfaction

Overall satisfaction with reconstruction: Women were asked to indicate how satisfied they were with their recon-

I am always looking over my shoulder, just thinking, “I hope it doesn't come back.” (The anxiety) comes and goes. I can go for weeks and then months and think, “A piece of cake. There is nothing to this.” Then all of a sudden something will happen. Race for the Cure is coming up. I always participate. I don't do that without thinking about it and bringing it all back. Coming tonight is certainly a step of—“Am I OK with this?” It is always there. It is right below the surface.

Figure 2. Fear of Recurrence

I remember sitting there with my husband, and the plastic surgeon walked in and said, “I am so sorry to hear about your diagnosis, but I am the good guy in the story. I am here to make it a positive thing.” The reconstruction is the positive part! Reconstructive surgery was a bright spot for me because it took my mind off of the cancer and into plastic surgery. Because I never felt that I had lost something, I consider this a successful surgery. The reconstruction really does help you move on. It gave me a sense of feeling like, “I am still going to look normal and I am going to *be* normal.” I can't remember the last time I wore a bra, and I am a runner, too. I think, “Wow, what a great benefit that is,” and they are very comfortable.

Figure 3. Satisfaction With Reconstruction

structions on a scale from 1 (very dissatisfied) to 10 (very satisfied). Eleven women gave satisfaction ratings of 8 or 9; one woman rated her satisfaction as a 1; the rest of the group gave ratings of 5 (three), 6 (one), and 7 (one). When asked for the reasons behind their satisfaction ratings, some women implicitly compared reconstructive surgery with other difficult aspects of breast cancer diagnosis and treatment; other women considered reconstruction successful because it helped them regain a sense of normalcy. A woman who was very active physically and had bilateral implants was pleased that she could be comfortable without wearing a bra (see Figure 3).

Concerns with symmetry and naturalness: In contrast to these reasons for satisfaction, women's comments about the final appearances of their reconstructed breasts often were lukewarm (see Figure 4). Some of the less positive remarks focused on symmetry. Others involved the women's feelings that reconstructed breasts looked or felt unnatural. Indeed, the reasons two women had their implants removed were symmetry and naturalness. Several of the women qualified their ambivalent remarks about satisfaction, suggesting that it would be unfair to have expected too much (see Figure 5).

Moving Forward: Advising Others

As they have moved through their breast cancer treatment and beyond, some women have found it rewarding to counsel other patients with breast cancer. One participant said she tells other women what questions to ask. Another received a copy of a prayer from someone and has copied the prayer and sent it to others who have been diagnosed with cancer. When another participant called a newly diagnosed patient at the request of an APN, she said she just found herself saying, “You will get through this.”

It is similar enough to the other breast, so I don't feel that I look outlandish. It sort of looks like the other one. I thought it would look a little better than it did. It's formed like a croquette ball. It is not as natural as you would like it to be. I don't think they look very natural, and I don't think they feel very natural.

Figure 4. Concerns With Breast Symmetry and Naturalness

It is not natural, I mean it's not me, so it certainly would not be a "10."

A "10" would be hard to have because it is not your original. I say I am not real satisfied with my reconstruction, but my other saying is, "God didn't make me perfect the first time, and I can't expect a surgeon to make me perfect the second time around."

Figure 5. Qualifications of Remarks About Satisfaction

When asked what advice they would give to women who are newly diagnosed with breast cancer, participants offered many suggestions. Some focused on the processes of decision making and medical care, such as advice to take someone along to doctor appointments, talk with someone who has been through the same type of surgery and treatment, and select a plastic surgeon who "takes into account what you want rather than what they think is best for you." Other advice focused on improving QOL (e.g., through humor) and getting back to normal after surgery by being active, going back to work, or taking a trip.

Reaction to Earlier Study

Participants were surprised that in the previous study (Nissen et al., 2001) women who had undergone postmastectomy reconstruction had lower QOL scores than women who had mastectomy alone. They offered three general hypotheses. One involved the issue of timing: "That study is done when you are . . . dealing with having to keep yourself going. If you come back to us five years later and ask us the same questions, how would we answer those questions? Would it be better later on?" Another suggestion was that, although adequate information was presented in preparation for reconstruction, some women might not have processed it completely: "At the time, I think some of the brain cells go into shock. You need another set of ears and eyes because yours are not necessarily functioning at full strength." Finally, a comment about expectations suggested that disappointment with reconstruction is inevitable: "When you have reconstruction, you have an expectation that you are reforming yourself. . . . You think it is going to look exactly like the other one. You don't have that expectation if you aren't going to do that. So you can see how there is going to be disappointment. There has got to be disappointment involved that would not be there otherwise, because you obviously know what to expect if you are not having reconstruction."

Discussion

The quantitative, prospective study of QOL after breast cancer surgery showed that women who underwent reconstruction had greater mood disturbance and lower well-being than women who did not (Nissen et al., 2001). The possibility that women undergoing reconstruction might have had unrealistic expectations of the surgery seemed plausible because it has been a general concern in plastic surgery (Schain et al., 1984). The findings of this focus group study, however, do not indicate any strongly held expectations for reconstruction that were not met or that were a source of serious disappointment. Indeed, some women stated that they had no explicit expectations regarding the surgery because their focus at that time was on surviving cancer rather than on reconstruction. Research on patient expectations and

satisfaction by Fitzpatrick and Hopkins (1983) suggested that this absence of specific expectations might be more general. They reported that patients' expectations before medical visits for the evaluation of headache "were so tentative in form that they were unlikely to be the basis of strong reactions afterwards."

The women received much information from several sources and felt well informed before their surgery. Despite this preparation, many of them reported aspects of care and recovery that were more difficult than expected, particularly the level of pain and the inconvenience of drains. Because these events are more likely to be experienced after mastectomy with reconstruction than after mastectomy alone, they could have contributed to lower QOL scores in the immediate postoperative period, but probably not beyond.

Perhaps the only unrealistic expectation that was presented to some of the women was that with reconstruction they would forget that they had had breast cancer. Women cited this comment from their plastic surgeons as a reason they decided to have reconstruction, but whether they actually internalized and held this expectation for themselves was not clear. The participants believed that a woman never forgets that she has had breast cancer, and several expressed significant levels of anxiety regarding recurrence. Nevertheless, some indicated that reconstruction had helped them move on and return to normal, a response that has been described previously (Neill, Armstrong, & Burnett, 1998).

With one exception, participants' ratings of their satisfaction with reconstruction were moderate to high. Other studies reported that women who had reconstruction typically were satisfied with the decision (Handel et al., 1990; Noone et al., 1982; Rowland et al., 1993; Stevens et al., 1984), although they were no more satisfied with the decision than were women who chose mastectomy alone (Anderson, Rodin, & Ariyan, 1994; Rowland & Holland, 1989). Women gave generally high satisfaction ratings in this study even though many reported loss of feeling and hardening of reconstructed breasts and had additional surgeries to improve the outcome. Furthermore, the satisfaction ratings contrast with the absence of praise for the cosmetic outcome of the reconstruction. This combination might be a manifestation of a remark made by a subject in a study by Mock (1993): "It isn't like the real thing, but it's better than nothing."

Implications

In the process of helping women decide whether to have reconstruction, both alternatives should be presented as real and viable options. Although reconstruction improves aspects of body image following mastectomy, it does not improve other aspects of QOL, and instilling expectations that it will can be misleading. Women appreciate and should be given thorough information to prepare them for reconstruction and recovery. For aspects of recovery in which substantial variation exists (e.g., time until drain removal), the range of experiences should be provided.

Study participants wished that they had had before surgery more information about postoperative care of drains, the types of bras that would be comfortable, the use of prostheses as an alternative to reconstructive surgery, and, especially, pictures of reconstructed breasts. They also would have liked to have more information about the lack of sensation in reconstructed

breasts and the pulling sensation through the abdominal area that can occur after the TRAM procedure. In response to these concerns, breast cancer nurses at the researchers' institution developed a patient information pamphlet on breast reconstruction. Oncology nurses should be involved in presurgical education to prepare patients adequately for reconstructive surgery.

Conclusions

Breast reconstruction is an elective procedure intended to improve the QOL of women undergoing mastectomy. Participants in this focus group study indicated that reconstruction met the goal of making them feel and look comfortable in

clothing. They confirmed that recovery from breast reconstructive surgery can be difficult. The expectation that reconstruction would help them forget about breast cancer did not match the reality of their emotional experiences. Their reconstructed breasts, which did not look or feel like their own, provided a sensory reminder. Significant anxiety about their disease and fear of recurrence persisted despite reconstruction.

The authors thank David K. Wellisch, PhD, for making available the "Questionnaire for Patients Who Have Undergone Breast Surgery."

Author Contact: Mary J. Nissen, PhD, MPH, can be reached at nissemm@parknicollet.com, with copy to editor at rose_mary@earthlink.net.

References

- Anderson, S.G., Rodin, J., & Ariyan, S. (1994). Treatment considerations in postmastectomy reconstruction: Their relative importance and relationship to patient satisfaction. *Annals of Plastic Surgery, 33*, 263–271.
- Appleton, J.V. (1995). Analyzing qualitative and interview data: Addressing issues of validity and reliability. *Journal of Advanced Nursing, 22*, 993–997.
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today, 11*, 461–466.
- Dean, C., Chetty, U., & Forrest, A.P.M. (1983). Effects of immediate breast reconstruction on psychosocial morbidity after mastectomy. *Lancet, 1* (8322), 459–462.
- Fitzpatrick, R., & Hopkins, A. (1983). Problems in the conceptual framework of patient satisfaction research: An empirical exploration. *Sociology of Health and Illness, 5*, 297–311.
- Giacomini, M.K., & Cook, D.J. (2000). Users' guides to the medical literature. XXIII. Qualitative research in health care A. Are the results of the study valid? *JAMA, 284*, 357–362.
- Goldwyn, R.M. (1987). Breast reconstruction after mastectomy. *New England Journal of Medicine, 317*, 1711–1714.
- Handel, N., Silverstein, M.J., Waisman, E., & Waisman, J.R. (1990). Reasons why mastectomy patients do not have breast reconstruction. *Plastic and Reconstructive Surgery, 86*, 1118–1122.
- Hart, D. (1996). The psychological outcome of breast reconstruction. *Plastic Surgical Nursing, 16*, 167–171.
- Hart, S., Meyerowitz, B.E., Apolone, G., Mosconi, P., & Liberati, A. (1997). Quality of life among mastectomy patients using external breast prostheses. *Tumori, 83*, 581–586.
- Krueger, R.A. (1998). *Focus group kit: Vol. 6. Analyzing and reporting focus group results*. Thousand Oaks, CA: Sage.
- Mock, V. (1993). Body image in women treated for breast cancer. *Nursing Research, 42*, 153–157.
- Montgomery, L.L., Tran, K.N., Heelan, M.C., Van Zee, K.J., Massie, M.J., Payne, D.K., et al. (1999). Issues of regret in women with contralateral prophylactic mastectomies. *Annals of Surgical Oncology, 6*, 546–552.
- Neill, K.M., Armstrong, N., & Burnett, C.B. (1998). Choosing reconstruction after mastectomy: A qualitative analysis. *Oncology Nursing Forum, 25*, 743–750.
- Nissen, M.J., Swenson, K.K., Ritz, L.J., Farrell, J.B., Sladek, M.L., & Lally, R.M. (2001). Quality of life after breast cancer surgery: A comparison of three surgical procedures. *Cancer, 91*, 1238–1246.
- Noone, R.B., Frazier, T.G., Hayward, C.Z., & Skiles, M.S. (1982). Patient acceptance of immediate reconstruction following mastectomy. *Plastic and Reconstructive Surgery, 69*, 632–638.
- Noone, R.B., Murphy, J.B., Spear, S.L., & Little, J.W. (1985). A six-year experience with immediate reconstruction after mastectomy for cancer. *Plastic and Reconstructive Surgery, 76*, 258–269.
- Powell, R.A., & Single, H.M. (1996). Methodology matters—V. Focus groups. *International Journal for Quality in Health Care, 8*, 499–504.
- Pusic, A., Thompson, T.A., Kerrigan, C.L., Sargeant, R., Slezak, S., Chang, B.W., et al. (1999). Surgical options for early-stage breast cancer: Factors associated with patient choice and postoperative quality of life. *Plastic and Reconstructive Surgery, 104*, 1325–1333.
- Ratner, E. (1999). *The feisty woman's breast cancer book*. Alameda, CA: Hunter House.
- Reaby, L.L., & Hort, L.K. (1995). Postmastectomy attitudes in women who wear external breast prostheses compared to those who have undergone breast reconstructions. *Journal of Behavioral Medicine, 18*, 55–67.
- Reaby, L.L., Hort, L.K., & Vandervord, J. (1994). Body image, self-concept, and self-esteem in women who had a mastectomy and either wore an external breast prosthesis or had breast reconstruction and women who had not experienced mastectomy. *Health Care for Women International, 15*, 361–375.
- Ritz, L.J., Nissen, M.J., Swenson, K.K., Farrell, J.B., Spurduto, P.W., Sladek, M.L., et al. (2000). Effects of advanced nursing care on quality of life and cost outcomes of women diagnosed with breast cancer. *Oncology Nursing Forum, 27*, 923–932.
- Rowland, J.H., Desmond, K.A., Meyerowitz, B.E., Belin, T.R., Wyatt, G.E., & Ganz, P.A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. *Journal of the National Cancer Institute, 92*, 1422–1429.
- Rowland, J.H., Dioso, J., Holland, J.C., Chaglassian, T., & Kinne, D. (1995). Breast reconstruction after mastectomy: Who seeks it, who refuses? *Plastic and Reconstructive Surgery, 95*, 812–822.
- Rowland, J.H., & Holland, J.C. (1989). Breast cancer. In J.C. Holland & J.H. Rowland (Eds.), *Handbook of psycho-oncology: Psychological care of the patient with cancer* (pp. 188–207). New York: Oxford University Press.
- Rowland, J.H., Holland, J.C., Chaglassian, T., & Kinne, D. (1993). Psychological response to breast reconstruction. Expectations for and impact on postmastectomy functioning. *Psychosomatics, 34*, 241–250.
- Schain, W.S. (1991). Breast reconstruction. Update of psychosocial and pragmatic concerns. *Cancer, 68*(Suppl. 5), 1170–1175.
- Schain, W.S., Jacobs, E., & Wellisch, D.K. (1984). Psychosocial issues in breast reconstruction. Intrapsychic, interpersonal, and practical concerns. *Clinics in Plastic Surgery, 11*, 237–251.
- Schain, W.S., Wellisch, D.K., Pasnau, R.O., & Landsverk, J. (1985). The sooner the better: A study of psychological factors in women undergoing immediate versus delayed breast reconstruction. *American Journal of Psychiatry, 142*, 40–46.
- Stevens, L.A., McGrath, M.H., Druss, R.G., Kister, S.J., Gump, F.E., & Forde, K.A. (1984). The psychological impact of immediate breast reconstruction for women with early breast cancer. *Plastic and Reconstructive Surgery, 73*, 619–626.
- Wellisch, D.K., DiMatteo, R., Silverstein, M., Landsverk, J., Hoffman, R., Waisman, J., et al. (1989). Psychosocial outcomes of breast cancer therapies: Lumpectomy versus mastectomy. *Psychosomatics, 30*, 365–373.
- Yurek, D., Farrar, W., & Andersen, B.L. (2000). Breast cancer surgery: Comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting and Clinical Psychology, 68*, 697–709.