The Breast Surgery Gallery: An Educational and Counseling Tool for People With Breast Cancer or Having Prophylactic Breast Surgery

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The Breast Surgery Gallery is a unique and innovative computer program of digital photographs depicting sequential images of oncoplastic and prophylactic breast surgery. Specialist breast nurse counselors developed the tool to provide education and assist in decision making for people facing oncoplastic and prophylactic breast surgery. This article presents a historical perspective of the development of the gallery and how it can be used during education and counseling. The authors discuss background validation, structure, and testing of the gallery, with case studies that illustrate its flexibility. Data from regular audits of the breast surgery gallery demonstrate the tool’s value. The Breast Surgery Gallery is a user-friendly tool that enables patients to make informed decisions while providing realistic photographs of the postoperative recovery phase.

A combined multidisciplinary breast clinic at Royal Perth Hospital in Western Australia includes a high-risk clinic, a symptomatic and surgical clinic, lymphedema management, and a breast assessment clinic. Altogether, about 7,244 clients were seen at all of the clinics in 2009. Specialist breast nurse counselors (SBNCs) at the breast assessment clinic provide education and counseling to patients and their families, as well as education and training to health professionals. In 2009, 443 people with breast cancer attended the clinic (Kydd, 2009), which is about a third of the people diagnosed with breast cancer in Western Australia (Threlfall & Thompson, 2007). Although the clinic caters to men and women, clients are predominantly female, with just six men diagnosed with breast cancer in the past six years (Kydd, 2009). In the process of counseling patients at the breast assessment clinic, SBNCs perceived that people were not prepared for the effects that breast surgery had emotionally and physically and identified a need for individualized information.

Patients’ Concerns Before Surgery

As many as 30% of women with breast cancer experience depression and anxiety within a year of diagnosis, with body-image issues and sexual difficulties significantly higher after mastectomy compared to breast-conserving surgery (Maguire, 2000). Discussing treatment options, involving patients in the decision-making process, and offering immediate breast reconstruction have improved satisfaction and reduced psychological morbidity (Ananian et al., 2004; Fallowfield, Baum, & Maguire, 1986; Heller, Parker, Youssef, & Miller, 2008; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002; Whelan et al., 2003). However, half of those diagnosed with early breast cancer do not participate in the surgical decision, which may be related to an information deficit influencing their ability to make informed choices (Waljee, Rogers, & Alderman, 2007).

SBNCs at the breast assessment clinic noted fears and concerns raised by people facing surgery for breast cancer, including the following:

At a Glance

- The Breast Surgery Gallery is a computer program of digital photographs depicting sequential images of oncoplastic and prophylactic breast surgery.
- By matching sequential images to clients by age, bra size, and ethnicity, the tool provides a realistic idea of postoperative results at staged intervals until 12 month after surgery.
- Case studies illustrate how the gallery can be incorporated into counseling sessions to assist patients who are making decisions about available surgical options.

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• Fear for survival: “Will I die from this cancer?”
• Fear relating to treatments: “How sick am I going to be? Will I be able to continue to care for my family? Will I be able to continue to work?”
• Fear of not being in control: “My life has changed so drastically in such a short period of time, I don’t feel like it’s my life anymore!”
• Sexuality and body-image issues: “Will my partner still find me attractive if I only have one breast? Will I ever feel sexy again?”
• Loss of role, as a mother, wife, or valued member of the work force.

Furthermore, the SBNCs noticed that the concerns appeared to be magnified in people electing to have reconstruction of their breasts. Discussion with a clinical psychologist confirmed the observation, as well as identified other problems that emerge frequently after surgery (WA Statewide Breast Cancer Clinical Psychology Service, 2000).

• Distress related to asymmetry of the breasts, particularly with unilateral reconstruction
• Unawareness that the natural breast could not be recreated
• Unawareness that a number of surgical procedures may be needed to complete the breast reconstruction
• Unawareness of the time to fully recover
• Distress related to not liking the feel of the reconstructed breast, particularly with tissue expanders and implants

The problems observed at the clinic and reinforced by the clinical psychologist also were identified in the healthcare literature (Beaver et al., 1996; Fallowfield et al., 1986; Rolnick et al., 2007). Collectively, they served as a catalyst that propelled the SBNCs to see what could be done to better prepare people for the reality of their surgeries. Available aids included a 36-page booklet titled Breast Reconstruction: Your Choice (Cancer Council of Victoria, 2000), a 21-minute video titled “Breast reconstruction: Your decision” (Tewksbury, 1997), and pre- and postoperative photographs used by some surgeons. The video included women discussing their experiences of reconstructive surgery, including the rationale for their decision and the outcomes. However, several years had passed since some of the women had had their surgeries, and no interaction was possible. Although it was factual and provided explanations and accompanying images, the booklet produced and regularly updated by the Cancer Council of Victoria was not individualized or interactive. Finally, the before-and-after photographs used by some surgeons were limited in number and were not age, size, or ethnically matched; therefore, many women could not relate to the pictures. All women had access to available resources, but at times resources were not appropriate or limited by personal choice.

Although decision aids such as decision boards, audiotapes, videotapes, pamphlets, CD-ROMs, and interactive multimedia are now well known (Heller et al., 2008; Waljee et al., 2007), a literature search in early 2000 did not identify a program which corresponded with what the SBNCs visualized. The SBNCs envisaged a program that would prepare patients preoperatively with tailored step-by-step education, providing support and counseling. Realizing patients needed to understand the impact of the proposed surgery, the SBNCs believed that a program was needed that would suit a range of women, from those in their 30s to those in their 70s, from those with small breasts with those with large breasts, even if they were having the same surgery. The SBNCs envisioned a program that was able to match surgery, age, bra size, and ethnicity for each person. They were unable to find a resource so subsequently developed a program known as the Breast Surgery Gallery (BSG).

Development of the Breast Surgery Gallery

The BSG is a freestanding computer program of digital photographs depicting real-life, deidentified, sequential breast surgery images. The purpose of the gallery is to address issues frequently faced by people who have breast cancer or who are undergoing prophylactic breast surgery and to assist them in making informed surgical decisions by demonstrating what may be surgically feasible. To achieve this, the gallery design includes categories of surgery type, age, bra size, and ethnicity. It includes preoperative images depicting natural breasts and a series of postoperative images. Because radiotherapy and subsequent surgery can affect the healing process, a one-year postoperative time frame provides a realistic representation of the final achievable cosmesis. Sequential images taken preoperatively, one to two weeks postoperatively, and 6 months and 12 months postoperatively capture the process to include radiotherapy changes and additional surgery. Postoperative images are timed to coincide with regular follow-up appointments. Breast surgeons and hospital management supported the idea of the program. Because it was considered a quality-improvement program, additional approval was not required.

The Breast Cancer Foundation of Western Australia provided funding for a digital camera and laptop computer. The gallery was developed as a stand-alone program so that access could be monitored and so that the BSG could be demonstrated in any room of the clinic. Functionality available within Microsoft® Windows® allowed the gallery to have categories and subcategories. Folders were generated to identify surgery type (i.e., mastectomy), and then subfolders were created to identify age group, bra size, and ethnicity. Ethical issues were addressed; written consent was obtained for the breast images to be stored within the gallery and a copy of the consent was given to participants. Those who agreed to participate were known to the SBNCs, and photographs taken by the SBNCs were obtained during clinic or other hospital appointments. Images stored in the BSG were deidentified, and a code was developed to recall images. When not in use, the BSG is stored securely in the breast assessment clinic.

Initially, a trial of the BSG concept was conducted involving a small sample of 10 women, with two in each of the following surgical categories.

• Mastectomy with no reconstruction
• Wide local excision or breast-conserving surgery
• Implant reconstruction (after mastectomy)
• Lattisimus dorsi flap reconstruction (after mastectomy)
• Transverse rectus abdominis myocutaneous (TRAM) flap (after mastectomy)

When possible, one woman 49 years or younger and one 50 years or older was selected, with a different bra size for each category. The trial continued until sequential images were
complete for each category. About 35–40 people, including health professionals and potential consumers, then viewed the images within the gallery.

Feedback from the BSG was positive. One nonmedical person commented on the value of an image of a participant wearing a bra 12 months after surgery. At that stage, she could see that nobody would know the person had had a mastectomy when she was dressed. This comment was important, and future gallery collections included images of women wearing bras prior to surgery and postoperatively, up to and including the final images at 12 months. Comments indicated that the images helped people move forward to the next phase of treatment with increased confidence. People felt more knowledgeable about the process as well as the surgery and more in control of what was happening to them and why. The decision to expand and develop the BSG was made in 2002, addressing the suggestion that “when surgical reconstruction is possible, patients should be given every opportunity to talk at length about possible complications, to view photographs of a range of surgical outcomes, and to explore how this surgery will suit their current lifestyle” (Maguire, 2000, p. 86).

Personalizing the Breast Surgery Gallery

A unique characteristic of the BSG as a visual tool is that it enables clients to have realistic expectations of what is surgically achievable. It also provides an opportunity for a one-on-one consultation with an SBNC who can provide education, explore and discuss issues, and address fears and concerns. People who attend the breast assessment clinic have seen their surgeons and know their diagnoses and surgical options. To enable SBNCs to assess each individual, consultation begins with an open question: “Tell me what you understand so far.” The ensuing discussion is influenced by the response to that question, but preidentified key issues are addressed during the session, which includes viewing images in the BSG. After an SBNC confirms the type of surgery, age group, bra size, and ethnicity, she retrieves a series of 10–15 images that start before surgery and progress to 12 months after surgery, taken with and without a bra from various views. The images form the basis of the counseling and education session. Patients view images on screen and do not take copies home.

Advantages of the individualized process are outlined in Figure 1, and the following case studies illustrate the use of the gallery.

Case Study 1

S.L., an Asian woman 33 years of age, bra size US 34B (UK 34C, AUS/NZ 12B, EU 75C), required a mastectomy to surgically remove breast cancer. Immediate breast reconstruction at the time of the mastectomy was discussed, and the plastic surgeon offered two options: lattisimus dorsi flap reconstruction with an implant or implant reconstruction alone. S.L. was considering having another child, and a TRAM flap was not in her best interest if she were to pursue pregnancy. S.L.’s plastic surgeon suggested that the options would provide acceptable cosmesis.

- Patients inspect images of the type of surgery they have discussed.
- Pre- and postoperative images over a period of 12 months allow them to appreciate the healing process and the resulting cosmetic outcome.
- Clients can imagine potential outcomes for themselves when reviewing images of patients with similar age, bra size, and ethnicity.
- Patients have an opportunity to view more than one surgical option. For example, when a mastectomy with or without immediate breast reconstruction is offered, patients can explore surgical options using the Breast Surgery Gallery as a decision-making tool, to assist them with informed decision making.
- The Breast Surgery Gallery provides an opportunity to discuss sensitive issues such as body image and sexuality.
- Issues such as recovery time, absence from work, and lifestyle can be addressed.
- Viewing images reinforces the realization that the surgery is oncoplastic and not breast enhancing or cosmetic.

S.L. wondered whether she would be able to care for her children, aged three and six years. Her husband, an accountant, worked long hours, and she had no other family support. Additional concerns were body image, future fertility, and the possibility of breastfeeding another baby.

Images from the BSG were selected to match S.L.’s age, bra size, and ethnicity in the recommended surgical procedures (see Figure 2 for some of the images). Viewing images of both surgical procedures from the preoperative stage to 12 months afterward allowed S.L. and her husband to:

- See the immediate postoperative appearance, including drains and dressings.
- See changes in the reconstructed breast over a 12-month period.
- Discuss concerns about physical limitations after surgery and how long her husband would need time away from work to care for his wife and young family.
- Address sexuality issues in the context of the consultation. Some men withdraw from their partners in response to the postoperative appearance (Sheppard & Ely, 2008), and exploration of BSG images helped prepare them for the reality of surgery.
- Understand and accept that S.L. was not having cosmetic surgery, but oncoplastic surgery, and appreciate the difference. The opportunity to view images of the recommended surgical options and to discuss the options with an SBNC assisted S.L. in making an informed surgical decision. Decision-making aids such as the BSG are known to promote communication between patients and healthcare workers, as well as patients’ subsequent involvement in the decision-making process (Waljee et al., 2007).

Case Study 2

J.S., a 58-year-old Caucasian, bra size US 38DD (UK 38E, AUS/NZ 16DD, EU 85F), was an only child and lived with and cared for a frail mother. She was employed part-time in a small local family business but believed that her employer would not be tolerant if too much leave was taken for treatment. The surgical

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options discussed with J.S. included breast-conserving surgery followed by six weeks of radiotherapy, and mastectomy with or without immediate or delayed reconstruction. J.S. was advised that if she preferred mastectomy and reconstruction, a TRAM flap would present her with the most acceptable cosmesis.

J.S. was concerned about the length of hospitalization. Her mother refused respite care, so a long hospital stay was out of the question. She also was concerned she would lose her job if unable to work for too long. Although she did not enjoy the work, it was within walking distance of her home and was convenient.

A series of appropriate images were selected (some are shown in Figure 3) and used as the basis for J.S. and the SBNC to discuss the surgical options and what they meant for J.S. The cancer was suitable for breast-conserving surgery and, provided she had adjuvant radiotherapy, would give the same prognosis as a mastectomy. Her stay in the hospital would be minimal, the same length of time as a woman having a mastectomy. After viewing the surgical options, J.S. requested bilateral mastectomy with no reconstruction. Because it appeared that J.S.’s own needs were not considered, the SBNC asked J.S. what brought her to the decision. Subsequent discussion enabled J.S. to explore choices she may have made if she had only herself to consider, and whether the choice would have been the same.

This case demonstrates the value of the BSG in exploring psychological and psychosocial issues. The versatility of the BSG makes it an educational tool and a means for SBNCs to address individual concerns and issues, offering appropriate counseling, support, and referrals.

**Accessing the Breast Surgery Gallery**

The BSG is a free service offered throughout Western Australia. A Web site (www.rph.wa.gov.au/Breast_Clinic/breastgallery.html) gives an overview of the service and provides a referral form to download. Referral can be made by a healthcare professional or a woman herself. However, self-referrals are asked to provide contact details of their general practitioners or surgeons to permit the SBNCs to verify the diagnosis and surgical options and subsequently tailor images to the woman’s requirements. No images are available on the Web site to protect those who participated in creating the BSG and to maintain the counselling and educational focus of the program.

Women living in the metropolitan area or able to visit the city are invited to make a one-hour appointment to view the images. With the woman’s agreement, the SBNCs recommend that a partner or chosen support person also attend. This facilitates
discussion after the session and helps women understand and remember information. Women who are having immediate reconstruction are encouraged to consult their breast specialists or plastic surgeons to discuss surgical options prior to viewing the gallery because they may not be suitable for one or more types of reconstruction.

Rural women who are unable to attend the clinic receive hard copies of appropriate images at their homes. A subsequent telephone consultation is arranged with an SBNC. This is an opportunity to address educational, emotional, and practical issues and to provide information about local support agencies. Although limited and without nonverbal nuances to help guide assessment of psychological state, the telephone conferences provide rural women with an opportunity to discuss surgical options in consultation with an SBNC.

**Evaluation of the Breast Surgery Gallery**

Since the initial trial, the BSG has been audited annually to provide feedback on the effectiveness of the service. Questions asked in the audit relate to the BSG and its use during counseling. The audit tool collects binomial (yes or no) and ordinal data with five options ranging from not helpful to extremely helpful to gather data on the perceived helpfulness of the BSG in elucidating the consequences of proposed surgery and in helping patients to make decisions regarding surgery.

Binomial data gauge negative feelings experienced when patients view the BSG and determine whether the BSG helped decision making. Qualitative data also are gathered from written comments. Recent data suggest that the gallery is helpful for people facing oncoplastic breast surgery: 94% (n = 32) said the images were valuable, and 95% (n = 41) agreed that the session with an SBNC assisted their understanding of their surgeries. A further 84% (n = 36) indicated that the session with an BSG assisted their decision making regarding type of surgery. Negative feelings were not experienced by the majority (78%) when viewing the gallery.

The following excerpts illustrate aspects of the BSG that were valued. Although “confronting,” the images provided realistic expectations of outcomes. “The BSG enabled me to develop realistic expectations of how I might look post-surgery.” “Showed the reality of the surgery, which was very helpful but also confronting.” “It is very confronting, but if that is how you are going to look, you need to know so you are more able to deal with it—so you really must view.” “Grief over changes to come, but it was helpful to have realistic expectations.” “Images confronting initially, however made expectations realistic.”

Support provided by the SBNC service was captured in the following citation: “Being prepared and supported prior to viewing and during was valuable and appreciated.”

Some comments highlighted a need for additional images for some body and bra sizes. Indirectly, this underscores the value of matching age and bra size. “There weren’t enough women my size or age I could relate to.” “It was very interesting and useful; however, more photos of small breasts (like mine) would be useful.”

The final comments remind healthcare professionals of the personal loss, fear, and shock that precede this type of surgery, as well as the assistance that can be provided by an education and counseling tool such as the BSG: “Whilst confronting, I found it almost a relief to see photos instead of just imagining what it might look like.” “I found it very reassuring. Takes away the fear of some of the unknown.” “Initially, I saw the bruising on the lady’s body, I was a bit shocked, but after the gallery consultants explained further, I was better.”

**Conclusion**

Decision aids increase knowledge, increase satisfaction, reduce anxiety (Heller et al., 2008; Waljee et al., 2007; Whelan et al., 2005), and promote patient involvement in decision making for breast cancer treatment options. Although involvement in decision making has demonstrated psychological benefits (Beaver et al., 1996), not everyone desires to be actively involved; some prefer to collaborate with their surgeons, and others prefer a passive role when choosing treatment options (Keating et al., 2002; Waljee et al., 2007). Regardless of decision-making style and preference, education and counseling are essential aspects of care. The value of the BSG is that it can be used to educate and counsel, as well as enable clients to picture themselves after surgery and to prepare for the changes. In a recent qualitative study which asked, “What one thing do you wish you had known before your prophylactic mastectomy?” many respondents said they wished they had seen photographs to better prepare them for the final result (Rolnick et al., 2007). The BSG fulfills this wish in a wide range of oncoplastic and prophylactic breast surgery options.

The idea for the BSG emerged from a perceived unmet need. Since its inception, the gallery has evolved and developed with the addition of new images. The gallery has been in use for eight years, repeatedly demonstrating its value as an educational and counseling tool. Evidence of this is clear from comments provided as feedback. In addition, each year more patients are referred to view the BSG prior to their planned surgeries by specialist breast surgeons. From 2006–2009, 377 clients viewed the BSG, with the numbers increasing steadily from 79 in 2006 to 119 in 2009. As surgical techniques improve and new procedures are introduced, images will be included for demonstration in the gallery. Rather than being a complete, finalized, marketable program, the BSG is an evolving work, tailored to the surgical treatments undertaken in Western Australia. However, the concept is simple and uses available technology, so developing a gallery is a manageable undertaking. With limited financial outlay, a user-friendly gallery of resources was developed to assist SBNCs in supporting people facing oncoplastic surgery. Limitations of previous resources provided the catalyst for the BSG, combined with the belief that a better service could be provided. Consequently, a unique and individualized counseling and educational tool is now part of the arsenal of resources employed by SBNCs to benefit people they counsel.

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