

**Breast Cancer Survivors' Body Form
and
Satisfaction with Breast Cancer Specific Products
(Brief report on part 1 of multi-part study)**

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Background

Part 1: Fifty-two non-pregnant female breast cancer survivors were recruited from eight of 24 identified active support groups, from an initial compilation of approximately 48 groups, throughout the state of Minnesota and in Western Wisconsin. Participants were recruited by contacting breast cancer support group coordinators, word of mouth, and from a posting on the Masonic Cancer Center Clinical Trials website. They completed one questionnaire delineating basic cancer diagnosis and treatment information and satisfaction with a number of breast cancer related wearable products and completed a body satisfaction instrument. Questionnaires were mailed to survivor group coordinators, distributed to group members by the coordinators and returned in postage-paid envelopes.

Part 2: Forty-one of the participants volunteered for and 25 completed an additional 45-60 minute research session in the Human Dimensioning© Laboratory including weight measurement, two 3-dimensional laser body scans, the FACT-B+4 quality of life questionnaire, and an individual interview expanding on the answers to their initial questionnaire. Results of the Part 2 study are reported separately.

This paper is a brief report of Part 1 of the study.

Participants--Part 1

Participants (n= 52) were ages 36-78 years, with a mean age of 59 years. Mean survival time since diagnosis was 9 years, with a range of 8 months to 28 years. The participants experienced a range of treatments (Table 1). Seventy-two percent of participants were treated with mastectomy surgery (27% unilateral, 45% bilateral). Approximately one-third (33%) of the women had reconstruction surgery. Fifty-five percent had radiation therapy and 65% lymph node dissection. Likewise, women were diagnosed at all breast cancer stages: 11.5% “0” stage referring to a pre-cancer that was treated, 25% stage 1, 26.9% stage 2, 17.3% stage 3, 7.7% stage 4, and 9.6% didn’t know or did not recall.

Table 1. Participants’ Breast Cancer Treatments

Treatment	Percent
Mastectomy:	
One breast (unilateral)	27%
Both breasts (bilateral)	45%
Lumpectomy (some eventually had mastectomy surgery)	
One breast	41%
Both breasts	2%
Lymph node dissection	65%
Sentinel node biopsy	55%
Radiation therapy	55%
Reconstruction	
One breast	8%
Both breasts	25%
Reconstruction type (percentage of total having reconstruction)	
Implants	23%
With own tissue (tram flap, etc.)	4%
Own tissue and implants	4%

Participants’ Discomfort at Treatment Site

Sixty-five percent indicated that they experience some discomfort at the surgery site with 49% saying that the discomfort interferes with wearing a bra. Thirty-four participants described the discomfort with description of painful or numb sensation (33%), scar tissue with painful swelling (29%), muscle pain with motion (15%), and discomfort from radiation (5%). Eighteen percent voiced distinct complaints that did not fit into these broad categories.

Women who said they experience pain or numbness described the experience saying:

“sensitivity under arm”

“A lot of soreness left chest and goes under armpit. I don’t know if it is muscle or what---I don’t know who to ask or where to go. Neither my oncologist nor my regular doctor has any answers”

“pain, scarring, numbness and tingling”

“tram flap area—stiff and sore standing, stitch near nerve in groin—healing now”

“pain where the incision is under the arm—swelling by end of the day”

“loss of feeling”

“on the side where I had 23 lymph nodes removed, I still have pulling.”

Women who said they have scar tissue with swelling said:

“because breast tissue was left (unfortunately!), different amounts on the two sides, and kind of under my armpit on the right, it took a long time for me to not constantly be aware of that unwanted tissue in my armpit.”

“I have a fluid filled lump in my breast that causes slight pain if compressed.”

“swelling in the breast and side of chest/abdominal area on right side.”

“tightness, swelling, tingling”

Women described pain with motion:

“when I over-do activities or I work out too long.”

“I get a twinge or a tightening of muscles when I reach across my body to the right. Then I know to stretch my left arm out and up and stretch my chest.”

Effects of radiation treatment were described as, “tenderness in the area and scarring from radiation which is also tender.” One woman described discomfort immediately after surgery saying she had, “drain tube discomfort after mastectomy and after reconstruction surgery.”

Several women described discomfort related to wearing apparel saying:

“if (I) wear a prosthesis too long it begins to press on a nerve.”

“Anything binding my chest is uncomfortable.”

“(I) needed a procedure where latissimus dorsi muscle relocated to a “hole” in my chest---bra rubs on this muscle under my R. arm.”

Satisfaction with Breast Cancer Specific Products

Participants were asked to rate their satisfaction with products including mastectomy bras, breast prostheses, and lymphedema sleeves. Open-ended responses provided more detail on women’s reasons for their rating and also gave participants the opportunity to suggest product improvements.

Table 2. Satisfaction/Dissatisfaction with Products Designed for Breast Cancer Survivors*

Product Type	Valid N	Range	Mean	Media	Mode
Mastectomy bras	29	1-7	3.09	3	2
Breast Prostheses	24	1-7	3.42	3	3
Lymphedema Sleeve	15	1-6	3.43	3.5	5

*7-point scale with 1 very satisfied and 7 very dissatisfied

Mean, median, and mode are 3 kinds of “averages”. The “mean” is the “average” you are used to where you add up all the numbers and then divide by the number of units. The “median” is the “middle” of the value in the list of numbers. To find the median the numbers must be listed in numerical order, then count from each end of the list to find the “middle” number. The “mode” is the value that occurs most often. If no number is repeated then there is no mode for the list of numbers. The “range” is the difference between the largest and smallest values.

Mastectomy Bra Satisfaction/Dissatisfaction

Twenty-six of the women said they wear or had worn mastectomy bras. Participants rated their satisfaction with mastectomy bras on a 7- point scale (1 most satisfaction, 7 least satisfaction). The median score was 3 and the mode was 2. In open-ended responses women expressed both positive (38%) and negative (62%) features of their mastectomy bras. Comfort was an important factor in evaluating the bras with the word *comfortable* or *uncomfortable* mentioned by 9 women. Positive responses related mostly to good support. Women gave more detail when providing information about dissatisfaction. A major complaint was “shifting,” “creep,” “pulling up,” especially on the prosthesis side (7 women). Irritation and rubbing was mentioned by several, as was poor fit and poor support. Three women described problems with the prosthesis being too large for the bra cup with edges protruding at underarm or top of cup. Four women were dissatisfied with appearance saying:

“(bras are) plain and drab. It’s hard enough to feel ‘sexy’ when you have just one breast and the bras do not help at all.”

“I miss being able to buy pretty bras. I hate having to be so self-conscious about leaning forward. The bra moves away from the chest wall and I’m afraid people can see my big scar. I hate how the bra ‘ripples’ and shows through sweaters.”

Several women recognized that products have improved over the years with one woman saying,

“The bras that I started with in 1986 were horrible. I actually went to wearing a *Bali* flower bra with underwires. It gave me lift in the left and my form was secure in the right. Now I have several different mastectomy bras because of (them) being better.”

Mastectomy Bra Improvement Suggestions

The participants were asked to suggest improvements for mastectomy bras. Most of the suggestions related to function with some fairly detailed descriptions. Three women wanted the prosthesis pocket redesigned for easier insert of the prosthesis. One suggested that the opening should be wider and perhaps close with a small snap. Textiles were a concern with several wanting softer textiles and/or “breathable” textiles perhaps borrowing from athletic wear technical textiles. Fit was an issue with one participant suggesting that bra manufacturers need to take into account more “accurate” measurements of women who have had breast surgery. Two participants felt that the style selection for larger sizes was very limited. Bra features that were mentioned included: provide styles for clothing with lower necklines and armholes, provide side panels of varying widths, front closures for the limited arm range of motion, underwire bras, and full-length bras (to the waist) to provide support that doesn’t rely on bra straps alone. Several participants used the opportunity to advocate for better styles in other categories such as swimsuits, sports bras, sleepwear and loungewear. One participant stated,

“I really would like to see someone address comfortable, attractive sleepwear for mastectomy patients as well. As a 34DD, it is currently a choice between looking very lopsided in traditional sleepwear or wearing a bra to achieve a symmetrical look.”

Another said, “Improvements still need to be made. More younger women are being diagnosed and we need more fashion available.”

Reconstruction Surgery and Effects on Product Satisfaction

Thirty-three participants had reconstruction surgery. Women who had unilateral mastectomy may have had reconstruction on the one cancer affected breast or reconstruction on both breasts to match or balance the remaining breast with the other breast.

When asked if reconstruction had affected the types or styles of bras they wear, 87% said yes. Most of these women do not wear specialized mastectomy bras or shop at stores that specialize in products for breast cancer survivors. Fifteen of these women described problems they had in finding bras after surgery. Approximately one-third of the women said they do not wear bras; some because the support of a bra is no longer needed, one because the bra cup shapes no longer “work” for her, and two described discomfort when wearing a bra.

Problems Identified in Bra Selection After Reconstruction

One woman described problems immediately post-surgery when she could find “no workable bra because most are too ‘rubby.’” She also described problems accommodating surgical drains, a problem immediately post-mastectomy surgery. Two women mentioned asymmetry as a problem with one solving the problem with a padded bra. Silicone implants were a special concern for

several women in selecting bras; one stating that she had to be “careful” with underwire bras and another stating that her implants were “too rounded” so that it was difficult to find a bra to fit. Two of the women said had they to do it again, they would choose a smaller implant size.

Bra Improvement Suggestions for Women Who Had Reconstruction

Participants who had reconstruction surgery offered few suggestions possibly due to the fact that one-third now do not wear bras. Four women wanted more comfortable bras mentioning “soft” or “softer” and desiring more cotton fiber content. Implants seemed to cause some problems, but few suggestions were offered for bra improvement. One participant who had tram flap reconstruction surgery said her bras cause back discomfort where tissue was moved from her back to front torso to form a breast.

Prostheses Satisfaction/Dissatisfaction

Most participants who wear prostheses described the silicone-type with several mentioning alternative fiber-fill types worn for special use such as “leisure” or “swim.” Evaluations were in broad categories of weight and comfort or appearance.

Eight women liked their prosthesis saying they liked the weight of the prosthesis, specifically that it is “natural,” “good match” or weighted to “feel more normal.” One woman stated that she will wear only a light-weight “cotton-filled” type because it is light-weight and doesn’t rub on her incision. Another woman stated that she only wears the silicone prosthesis when “dressed up” because she likes the look, saying, “its a little heavier and it doesn’t shift.”

Negative statements were more prevalent, again falling into the categories of weight or comfort or appearance. Negative comments related to weight and comfort included:

- “expensive and heavy”
- “I’m approximately a “D” size and too heavy”
- “unbearable in heat”
- “perspiration issues in summer”
- “they flop around when I run”

Negative appearance related issues were described as:

- “feels fake”
- “not correct shape/size—falls between”
- “couldn’t find AA cup to match other side, so felt self-conscious”
- “It wasn’t me.” (participant eventually had reconstruction surgery)
- “moves up and shows over top of bra”

Prosthesis Improvement Suggestions

Prosthesis manufacturers recognize the difficulty of developing a prosthesis that closely resembles the natural breast in weight and texture, provides comfort especially in warmer environments, and is available in a range of sizes to meet the needs of women of all shapes and sizes. Women in this study responded with the same concerns, however two of the participants recognized that breast prosthesis design has improved over the years. The size and weight issues were voiced by women wearing size “C” cup or larger; however women wearing smaller sizes (AA) said they also could not find a form that provided satisfactory appearance. Several women complained of the cost.

In addition to size and comfort there were some unique suggestions. One woman wanted an adjustable form “so could adjust with weight fluctuations.” Two women thought the forms were not durable enough, one saying to develop an outer surface that doesn’t rip, tear or puncture easily and another suggesting a patch kit would be useful. Two women suggested more professional assistance for women including “train people to encourage women to get prosthetic that is the right size for her body size” and another wanting someone to provide information in the hospital after surgery saying she wasn’t given any information and no suggestions were offered when she asked.

Lymphedema Problems

Thirty-three percent of the respondents said they had been diagnosed with lymphedema. However, many women who were not diagnosed with lymphedema said they had experienced arm problems on their treated side. Twenty-five percent of those not diagnosed said they had problems with arm swelling, 41.6% with loss of feeling, 33.33% with restricted motion, and 12.5% described other problems including: frozen shoulder, cording, webbing, swelling on mastectomy side of body usually at end of the day, pain at scar site when muscle is stretched as in yoga exercises, any IV (intravenous) treatment on that arm causes swelling, isolated instances of swelling, permanent loss of feeling, tissue hard and painful, and pain when reaching.

One participant described her experience in detail saying:

“Acute lymphedema happened at end of chemotherapy. Wrapping of arm daily lasted 4 months with PT (physical therapy) 2-3 times a week. Coats and sleeves were very difficult—borrowing other sizes. Nursing uniform sleeves needed letting out, loose lab jacket fit over, very hot at times, but covered embarrassing ‘broken arm’ look.”

Lymphedema Sleeve Problems

Fifteen women provided satisfaction scores on lymphedema sleeves with scores ranging from 1 to 6, mean score of 3.43, median score of 3.5 and mode of 5. Women who need to wear a sleeve to alleviate problems seem to accept that it helps relieve lymphedema pain and discomfort with

over one-half saying their sleeve is comfortable, provides good compression, reduces pain, and one person said she likes the fit of her sleeve. One mentioned the difficulty of putting on the sleeve and another said that she has to daily wrap her arm in compression bandages to control swelling which she finds cumbersome and “archaic.” The functional problem that over one-half of the sleeve wearers identified was that the sleeve tends to roll down and not stay in place. One woman said the sleeve cut off circulation when it rolled down. Another said that the band around the thumb intended to anchor the sleeve was too tight and restricting. One mentioned the new sleeves on the market saying,

“I appreciate the good looks, and fun patterns. The sleeve and gauntlet is not too heavy or restrictive. It fit me better and suits my lifestyle.”

On the other hand, one woman remarked,

“I don’t like the color, heavy texture of garment, that it looks so medicinal and conspicuous.”

Lymphedema Sleeve Improvement Suggestions

When asked if they could suggest improvements few could provide any ideas or descriptions, one woman saying “they are what they are!” Several women restated what they said under the “problems” question wanting sleeves that are easier to put on and sizes for women with short arms. Several reiterated the appearance issues stating, “make them not so medicinal looking” and “better colors, less conspicuous.” One woman summed up her feelings by saying, “If someone could improve a compression sleeve they would receive a fortune.”

Breast cancer Treatment Posture Effects

Twenty-two women reported their cancer treatment impacted their posture with 12 women reporting that their posture improved with use of a breast prosthesis. The experience of altered posture and possible interaction with breast-cancer specific products is explored more fully in Part 2 of the study.

Study Part 2

Twenty-five of Part 1 participants continued with Part 2 of the study. Part 2 of the study included in-depth interviews, completion of a quality of life (QOL) questionnaire and body scans of each participant. Further analysis of questionnaire data, theme development from interviews and analysis of QOL data continues. Body scan data are being analyzed quantitatively and qualitatively. Protocols for measurement of arm volumes to measure lymphedema, as well as documentation of postural angles in the 3-dimensional body scans have been developed. Results of body scan processes and analyses may result in improved methods of diagnosing lymphedema and tracking changes. Body scan data may also be used in developing improved products.

Conclusions

Women in this study were fairly pleased with mastectomy bras and breast prostheses, some recognizing that these products have improved over the years. However, the problems that are still bothersome relate to the functions of weight of prostheses and heat (bras and prostheses); and limited choices of colors and styles for bras. These participants cope with discomfort, some related to worn product, some not. Participants' suggestions for product improvement may prove useful for mastectomy bra and breast prostheses manufacturers.

Lymphedema sleeves are seen as uncomfortable and unattractive although these participants appreciated the functions of the sleeves and the necessity of using them. There are opportunities for manufacturers to experiment with fit, function, and aesthetic features of wearable products for lymphedema. New methods of shaping and sizing wearable product for lymphedema treatment may be possible using body scan technology which is a component of Part 2 of this study.

Thank you to the Participants

The study researchers thank the study participants. We will pass along your experiences and knowledge to companies who can make a difference in design, production, and marketing of wearable product for breast cancer survivors.

Human Subjects approval was received before contacting potential participants.

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