Sweet dreams: Needs assessment and prototype design of post-mastectomy sleepwear

Sandra Tullio-Pow1, Rebecca Zhu2, Kirsten Schaefer1, Oxana Kolenchenko2, Joyce Nyhof-Young3
1. Ryerson University, School of Fashion
2. Faculty of Medicine, University of Toronto
3. Cancer Survivorship Program, Princess Margaret Hospital, Department of Radiation Oncology, University of Toronto

Abstract
In 2009, approximately 215,700 North American women were diagnosed with breast cancer [5]. Treatment typically involves breast tissue removal (mastectomy or lumpectomy) resulting in scarring, changes to breast size, and torso asymmetry. This study assessed sleepwear and lingerie needs of female breast cancer survivors and designed prototypes of functional, attractive sleepwear, scarce commodities for this cohort. Focus group discussions on sexuality, concealment, and clothing problems were audio recorded, transcribed, and thematically analyzed, and the researchers collected accompanying survey data (demographics, attitudes, and clothing preferences). Four focus groups (n=18) highlighted clothing concerns regarding accessibility and affordability, and provided specific recommendations on garment colour, comfort, cost, and cut. Participants sought sleepwear that considers seam placement—especially in the vicinity of surgery scars—silhouette, and neckline shape to ensure comfort and camouflage of torso asymmetry, and fabrics that compensate for chemotherapy-related hot flashes. Insights were gained about women’s satisfaction with ready-to-wear nightgowns/pyjamas, post-mastectomy apparel preferences, and links between clothing appearance/fit, femininity, and self-esteem. Prototypes incorporating both functional and inclusive apparel design principles were designed to resolve problems revealed in the needs analysis. The latest versions of the sleepwear are presented and future directions discussed.

Keywords
Breast cancer, mastectomy, sleepwear

Background
Breast cancer is the most prevalent cancer among women, with mastectomy and lumpectomy the most common surgical treatments for the disease. Surgery and accompanying radiation can result in scarring and tenderness, as well as changes to breast size, shape of the chest wall, and overall torso symmetry [27]. Both pre- and post-menopausal breast cancer patients also report chemotherapy-related hot flashes [7] causing sensations that vary from mild warmth to being soaked with perspiration, which impacts both sleep quality and clothing choices [13]. Following mastectomy, women may also experience anxiety, depression, and a negatively altered body image [1, 20], and they may struggle to find affordable clothing that is comfortable, aesthetically pleasing, and that makes them feel sexually attractive [16, 20]. Specially designed
Clothing can help post-mastectomy patients cope with physical disabilities and emotional distress resulting from disfiguring surgery [11, 12]. To improve the coping and quality of life of women with breast cancer related mastectomies, a major Canadian cancer research and teaching hospital established an innovative clothing design partnership with a Toronto-based university school of fashion.

**Clothing, Appearance Concerns and Self-esteem**

Research has revealed how fashion psychology enhances relationships between self-esteem, looking good, and feeling better [9]. For example, social comparison theory [14] posits that human beings evaluate themselves through comparisons to others, resulting in increased or decreased self-esteem [22]. Similarly, the development of one’s personal style or appearance is linked with the desire to achieve society’s cultural beauty ideal [30]. Women with mastectomies feel they do not match societal notions of idealized female figures; consequently, most women opt to wear prostheses and alter their clothing choices accordingly (e.g., wearing high necklines to cover cleavage) in order to model a traditional female aesthetic. Others may use apparel to camouflage less desirable characteristics and enhance attractive attributes. In either case, it is easier for women with mastectomies to achieve a positive effect on appearance through daywear than with sleepwear, and traditional nightgowns may negatively impact self-esteem [26, 30], body image, and sexual quality of life [4, 10] because they cannot easily disguise missing or asymmetrical breasts.

With continued improvement in breast cancer survival rates, more women are living longer with a variety of post-treatment sexuality and intimacy issues, which also affects their quality of life [15]. Clothing specially designed for and worn by these patients can improve body image and result in a more positive attitude towards body and self [11, 12, 31]. For example, investigations of post-mastectomy clothing preferences indicate that women with mastectomies were more satisfied with their bodies when clothed than when unclothed [2, 8]. The present research therefore aims to fill a need that exists for specially designed sleepwear and lingerie among this cohort of survivors.

**Theoretical Frameworks**

Two theoretical frameworks underpin our approach to clothing design to help women self-manage negative outcomes of breast cancer treatment. First, functional apparel design aims to engineer garments to meet wearers’ special needs by prioritizing comfort, mobility, and serviceability. These product features alone will not ensure consumer appeal and acceptance; proposed designs should be based on a model of user-oriented product development [29] and balance aesthetic, expressive, and functional clothing attributes [18]. Second, universal or inclusive design principles advocate that garment designs be usable by people of all ages and abilities [32]. Given that “the size and wealth of the group that needs special clothing is often perceived to be insufficient to merit the investment in design development and production” [34], universal design promotes viable “economies of scale” in mass production of specialized, innovative merchandise. From the survivors’ perspective, universal design minimizes psychosocial and economic concerns arising from their present need to shop at medical supply retailers for expensive specialty items. In addition, purchases of prostheses, brassieres, and other therapeutic garments often are not reimbursed by insurance policies [17, 21]. The financial means to compensate for apparel difficulties or feelings of inadequacy related to body image—particularly in the initial months after surgery—can be crucial to functional and psychological aspects of post-treatment recovery [6].
Purpose of Study
Phase I of the study sought to determine the sleepwear clothing challenges faced by breast cancer survivors. Focus group sessions were structured to determine: (a) satisfaction with ready to wear nightgowns/pyjamas; (b) sleepwear preferences; (c) selection criteria to be considered in the design of effective nightwear; and (d) relationships between sleepwear design/fit, femininity, self-confidence, and well being. Research questions included:

- What are the effects of mastectomy on appearance anxiety, body image, and sexuality?
- What are the lingerie and sleepwear concerns of women post mastectomy, specifically clothing problems and personal solutions developed?
- What selection criteria are prioritized for lingerie and sleepwear?

In Phase II of the study, we analyzed Phase I data and incorporated functional and inclusive design principles to develop sleepwear prototypes suited to the needs of our sample. Phase III of the study is currently undergoing ethics review, with plans to manufacture and field test design prototypes. Prototype design effectiveness and areas for improvement will be investigated. Our ultimate goal is to develop fashionable, affordable, and functional sleepwear for breast cancer survivors that enhances body image and promotes well being.

Methods
A leading Canadian cancer research and teaching hospital partnered with a Toronto-based university school of fashion to collaborate within a methodological framework of participatory design. This approach places a premium on the active involvement of the target audience as potential or current users in design and decision-making processes. The premise is that those who have a key use for a product must play a critical role in its development. The process ensures that the final design of an intervention is as relevant and beneficial to the user as possible, and considers the specific needs of a particular population. As such, the participatory approach to clothing design involves a user-centered methodology that explicitly enables end-users to voice their opinions and needs during the design process, thus ensuring that the end product is relevant to a range of individuals within the target population.

We selected the study sample from the hospital’s population of English-speaking, adult female breast-cancer survivors who had undergone a mastectomy or lumpectomy. Posters were displayed in the hospital. The names of eligible candidates, who had shown an interest in participating, were obtained confidentially from the hospital’s Breast Cancer Survivorship Program. Participants were also recruited from other breast clinics at the hospital. Patients were then contacted by phone or email to obtain consent.

This was a mixed-method study. Focus groups (facilitated by a second-year medical student) were used to qualitatively assess the lingerie and sleepwear needs of post-mastectomy breast-cancer patients. Surveys were used to assess socioeconomic status (SES) and affordability and accessibility of specially designed lingerie and sleepwear. Focus group discussions were audio recorded, transcribed, and anonymized.

Research Design
Surveys were completed prior to the focus-group sessions; they requested:

- Demographic information (age, marital status, ethnic origin, education, household income, and employment status);
- Lingerie and sleepwear preferences; and
- Affordability and accessibility of nightwear designed for post-mastectomy breast cancer patients.

The moderator’s guide for focus group discussions included topics such as:
- Impact of mastectomy on quality of life;
- Problems and difficulties with sleepwear and lingerie post mastectomy;
- Special needs for lingerie and sleepwear, and how they have (not) been met;
- Satisfaction with currently available lingerie and sleepwear; and
- Design preferences (e.g., fabric, style, colour).

**Data Analysis**

Questionnaire responses were entered into a spreadsheet and analyzed using SPSS. Participants were grouped according to SES by respondents’ total annual household income and education level attained. Responses regarding affordability and accessibility of specially designed post-mastectomy lingerie and sleepwear were cross-tabulated with respondent SES data. Sleepwear and lingerie preferences were tallied and preferences with regards to colour, design, and fabric noted.

Focus-group transcripts were analyzed within NVivo qualitative research software. Multiple coders subjected transcripts to descriptive thematic analysis. Text fragments were coded with specific ideas or concepts and grouped into larger categories and ultimately themes. Codes, categories and themes were compared between investigators and coding disagreements resolved by consensus. Major themes encompassing the data were generated [28, 33].

**Results**

Four focus groups were conducted with a total of 18 participants. Participant information is outlined in the sections that follow.

**Questionnaires**

**Demographic information**

The majority of participants (77.7%) were between the ages of 50-70 years; 17 group members were Caucasian and 1 participant was African Canadian. Most participants (66.7%) were married or lived with a partner, while others lived alone or with relatives. Half of the participants had a post-secondary degree or certificate; 6 had some post-secondary education but no degree; and 3 had graduate or professional degrees. The majority of respondents (61%) had household incomes above $71,000. Five participants had undergone breast reconstructive surgery.

**Lingerie and Sleepwear Preferences**

Most participants wore pyjamas for sleeping. Lingerie preferences included camisoles and chemises. Colour preferences included purple and black. Cotton was the most preferred fabric.

**SES, Accessibility and Affordability**

When asked whether specially designed lingerie and sleepwear on the market today are accessible (i.e., widely available and easily purchased in stores or online), most participants responded that they go to specialty stores for mastectomy bras, but continue to shop in department stores for sleepwear. As expected, participants with larger annual household incomes reported greater access to appropriate sleepwear and lingerie—participants whose annual household income exceeded $70,000 spent more on lingerie and sleepwear than participants whose income was between $51,000 and $70,000. However, irrespective of educational background or income level, all of the women thought that specially designed sleepwear and lingerie were somewhat or definitely overpriced.
Focus Group Themes

Physical and Emotional Impact of Mastectomy
Mastectomy surgery had an immediate physical and emotional impact on these women. They experienced fear when the bandages were taken off and most of them worried about scar formation. Some participants developed complications (hematoma and lymphedema), which limited functionality. Post-operative devices like shoulder pads and draining devices interfered with sleep and comfort. Participants were concerned about cancer recurrence and whether their daughters would develop breast cancer. They worried about how others would see their bodies and how their partners would accept and cope with changes; some were afraid of starting new relationships. Initial negative feelings towards their post-operation breasts hampered emotional recovery. One patient said, “[it] looks weird, doesn’t look nice; my body looks deformed.” Some participants were reluctant to look at themselves in the mirror, while others described a process of slowly coming to accept their new bodies.

Concerns Regarding Clothing
Most women were initially concerned about clothing fit. Post-surgery, they did not know what style of clothes to buy or where to purchase them. Some had to revamp their wardrobes; tight-fitting shirts and clothing with low-cut necklines were given away. Considerable frustration was associated with shopping for new clothes: “I go to the department stores and I can’t find anything and I hate walking into La Senza because I can’t wear anything in the store anymore, and it just makes me feel weird. I don’t even know where to go anymore.”

Finding mastectomy bras that are appealing was particularly problematic for these participants due to cost- and style-related factors. Most available designs were not aesthetically pleasing, or as one respondent noted, “Not pretty.” A lack of selection in colour and style was noted, and size limitations were a considerable problem; women with small breasts and those with very large breasts had trouble finding properly fitting mastectomy bras. It should be noted here that the embarrassing wardrobe malfunctions associated with prostheses, daywear, and especially bathing suits were nonetheless discussed with some humour by these women.

Needs and Preferences – The 4 Cs: Cost, Colour, Comfort, and Cut

Cost
Patients incur significant costs when purchasing mastectomy bras and prostheses; each item may cost between $80 and $200 CAD (i.e., 56 to 140 EUR, or 49 to 122 GBP). Additional costs were associated with purchasing new clothes and altering existing wardrobes. Most participants reported spending significantly more money on lingerie and sleepwear after surgery.

Colour
Participants preferred darker colours, such as purple and black, more than bright, shimmering colours. One woman stated, “I used to wear bright clothing and I don’t now. I wear darker clothing, because I just feel that you don’t notice as much if you are in something that is black or brown; but white doesn’t really work for me.”

Comfort
Participants preferred light, breathable material. Many women experienced nighttime sleep disruption due to hot flashes, and so cotton was the fabric of choice for comfort and absorbency. Desirable fabrics were those that did not irritate sensitive skin (e.g., no scratchy lace, elastic, or underwire) and garments included those without side seams that might rub against surgical scars; as one participant noted, “The big thing is don’t get the seams near our bodies; especially
if you have had an actual dissection. You don’t want seams running under your armpit, because that’s very tender and numb.”

Cut (design)

Most participants wanted a more stylish and aesthetically pleasing collection of sleepwear and lingerie, one especially designed for women with mastectomies that can also camouflage torso asymmetry. As one participant noted,

“A mastectomy] definitely changes the style of clothing that you wear or are able to wear. You can’t have anything that’s sort of low cut. … If you are moving, then suddenly people are seeing down your shirt and your skin is not the same on both sides because they removed your chest wall. So that would make a big difference.”

Some participants also suggested wider straps for mastectomy bras. Other comments related to needs and preferences are presented in Table 1.

Table 1: Participant clothing needs and preferences

<table>
<thead>
<tr>
<th>Cost</th>
<th>Colour</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Government assistance … will pay you a percentage of that [cost for mastectomy bras and prosthesis], but you’ve got to pay that up front. Somewhere you’ve got to get that money, and I just don’t have the money tree. So for many of us the cost is prohibitive.</td>
<td>• I usually don’t like black. Actually I like brighter colours like pinks and light blues.</td>
</tr>
<tr>
<td>• Well, I haven’t found any sleepwear that [is] specifically designed for women with mastectomies. … I mean if I found something I loved and it cost a bit more, I wouldn’t hesitate to buy it if I really loved it.</td>
<td>• I rarely wear black lingerie. I like kind of a cream-colour ivory, as opposed to a pure white. And I like pinks and blues.</td>
</tr>
<tr>
<td></td>
<td>• It is usually beige or white, you know. Give me something else. Bright red, if you have to, but that’s my feel and affordability too.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Comfort</th>
<th>Cut</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Okay I like comfort. I like sexiness, and I like to look pretty. So it must be pretty and comfortable.</td>
<td>• There are also times where you might want something for the whole night. For example, like if it’s just you, fine, it really doesn’t matter; but if I am with say a group of friends where I am the only one who has had to deal with cancer—we are in a hotel room sharing two to a bed—I just, not for my sake but for their sake, I might want to wear something that makes me look normal all the time.</td>
</tr>
<tr>
<td>• I remember just after my lumpectomy, I was extremely sensitive in my scar. I couldn’t bear any weight when any clothes [were] on it. And I couldn’t find anything. And just the idea of having clothes on me, it made me cringe.</td>
<td>• Something that is “with it.” Yes, that’s cute in style. Not something that your grandmother would wear.</td>
</tr>
<tr>
<td>• It has to be breathable, because with hot flashes, with the night sweats, and with medication and chemo putting you into menopause or whatever … it’s got to be something that is breathable.</td>
<td></td>
</tr>
</tbody>
</table>

Phase II – Design Development

Sleepwear development followed a traditional design process model (i.e., accept, analyze, define, ideate, select, implement, and evaluate) [34]. Using the data from focus groups, design ideation development prioritized styles that were both functional to this market segment and inclusive in appealing to the general female population. (See Table 2 for a summary of key design requirements.) A draped collar was created to camouflage torso asymmetry, and an accompanying camisole underlay with a lace insert was designed to disguise scars and cleavage unevenness. Attention to armhole depth was prioritized to cover surgery scars. A cropped jacket was created with prosthesis accommodation. Performance fabrics were
researched, prioritizing materials with a soft hand, superior absorbency, and wicking abilities. Three prototype fabrics were chosen:

1. Bamboo-cotton: Bamboo fabric has natural wicking properties that pull moisture (e.g., perspiration from hot flashes) away from skin. Cotton is highly absorbent; the fibre combination promotes cool, dry, next-to-skin comfort.

2. Coolmax polyester: A brand of man-made fibre engineered with an internal capillary structure that moves moisture away from the body through the fabric, where it can evaporate quickly, keeping the body cool and dry.

3. Silk jersey: An expensive luxury fibre with a natural luster; highly absorbent, it is also very comfortable next to the skin. Silk fibres are both strong and fine, creating a lightweight, durable fabric. Silk also has low conductivity, creating a comfortable micro climate around the wearer (e.g., cool during summer or hot flashes; warm in winter).

Table 2: Key design requirements of participants

<table>
<thead>
<tr>
<th>Comfort</th>
<th>Cut/fit</th>
<th>Durability</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Breathable</td>
<td>• Not low cut</td>
<td>• Seams shouldn’t roughen in the wash</td>
</tr>
<tr>
<td>• Cotton-like fabric</td>
<td>• Wider straps</td>
<td></td>
</tr>
<tr>
<td>• Wicking</td>
<td>• Camouflage breast asymmetry without</td>
<td></td>
</tr>
<tr>
<td>• Soft hand</td>
<td>prosthesis</td>
<td></td>
</tr>
<tr>
<td>• Free of abrasive surfaces</td>
<td>• Cover armhole scars</td>
<td></td>
</tr>
<tr>
<td>• Avoid seams near surgical scar areas</td>
<td>• No gaping at neck</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Style</th>
<th>Colour</th>
<th>Branding</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Pretty</td>
<td>• Ivory</td>
<td>• Non-irritating labels (i.e., screen</td>
</tr>
<tr>
<td>• With-it</td>
<td>• Red</td>
<td>print on fabric)</td>
</tr>
<tr>
<td>• Asymmetric</td>
<td>• Pink</td>
<td></td>
</tr>
<tr>
<td>• Sexy</td>
<td>• Blue</td>
<td></td>
</tr>
<tr>
<td>• Pyjamas</td>
<td>• Purple</td>
<td></td>
</tr>
<tr>
<td>• Camisoles</td>
<td>• Black</td>
<td></td>
</tr>
<tr>
<td>• Chemises</td>
<td>• Darker colours</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1: Sleepwear Designs
Sleepwear designs were then created (see Figure 1). To improve fit analysis, a dress form was “mastectomized” to simulate women’s physique in the intended target market. Finally, multiple sequential prototypes were pattern drafted, sewn, and critiqued on the dress form. Resulting sleepwear designs include long and short versions of a nightgown; a jacket with prosthesis accommodation, and a pyjama set.

**Discussion**

A more comprehensive understanding of the physical and psychological needs of breast cancer survivors who have undergone mastectomy has led to better treatments, carefully designed post-operative care and diverse support groups and resources. However, limited knowledge exists of the lingerie and sleepwear preferences of these women. In addition, only a few companies produce specially designed nightclothes for this population [19]. Functional yet appealing nightwear is neither readily accessible nor affordable for many of these women. Due to the out-of-pocket costs of breast cancer treatment and care, functional and attractive lingerie and sleepwear have become luxury items for some patients. Disparities in accessibility and affordability of lingerie and sleepwear for women from different socioeconomic groups were clearly apparent in focus group comments.

**Importance of Cost**

Participants from all socioeconomic backgrounds thought that currently available specially designed lingerie and sleepwear are overpriced. This negative price difference was seen as significant for women in all income brackets. Women with higher SES may have the financial means to purchase high-priced specialty clothing, but the perception of being overcharged remains constant. A reasonable price point will be important to ensure affordability for as many survivors as possible.

**Need for Improved Accessibility**

When comparing perceived accessibility by the income and education levels of these women, a non-significant trend was observed—as income increased, specially designed sleepwear and lingerie became more accessible.

Many specialty clothing stores are located in large urban centres. The majority of study participants lived outside metropolitan areas. In this study, women with higher SES had better access to urban centres and the associated specialty stores, as well as more discretionary income for clothing purchases than those with lower household incomes. To address disparities in accessibility for women with lower income who live outside urban centres, these specialty products should ideally be available in the ready-to-wear market rather than exclusively in urban and expensive specialty stores. Our prior work indicates that breast-cancer survivors prefer to shop for specially designed clothing, lingerie, and sleepwear in regular rather than specialty stores [23, 24, 25]. This restores a sense of normalcy and limits reminders of breast cancer. Such an understanding of the impact of SES on clothing affordability and accessibility is highly relevant to the future marketing and success of the new nightwear by prospective companies.

**Study Limitations**

The sample size was small, (4 focus groups comprising 18 women) and not highly diverse racially. In addition, women unable to communicate in English were excluded. Therefore, the preferences and experiences of a variety of cultural and ethnic groups may not have been reflected. However data saturation was reached within this sample, and we obtained a good understanding of rural and urban experiences. Still, a larger sample is needed to achieve statistical significance in survey data.
Future Directions: Phase III

The project’s final stage will field test the refined prototypes with volunteers from the Phase I focus groups to determine if design solutions work as intended. A field trial is a test of a product under conditions of actual operation or use. Consumers traditionally evaluate a variety of criteria prior to making purchase decisions, including those related to garment colour and fit; fabric comfort and durability; laundering procedures; and cost, quality, styling, and brand name [3]. While designers may speculate about consumer acceptance of many of these factors during product development, some elements of merchandise performance (e.g., fit, comfort, and care-related durability) are best assessed by the consumer through field testing, especially in the case of specialized apparel geared for a specific target market.

Anticipated Outcomes

This study aimed to provide a better understanding of the sleepwear characteristics that breast-cancer survivors value and the design requirements to meet those needs. The primary benefit of this sleepwear will be camouflage of torso asymmetry in an attractive and contemporary design. It is anticipated that this will raise the self-esteem of our participants and other survivors alike. The fabric’s wicking ability may reduce the detrimental effects of hot flashes and promote improved quality of life (e.g., better sleep quality). This is an issue of importance for breast-cancer survivors, as well as for peri-menopausal and menopausal women in the general population. Field trial results will provide information about garment performance, fabric suitability, and design practicality and appropriateness for both breast-cancer survivors and the general female population. Field testing will also help determine if the product is ready for mass production and distribution in retail stores.

It is one of life’s major challenges to be diagnosed with cancer, and yet another to have a breast removed. These sleepwear designs may improve self-concept, comfort, and improved quality of life for breast-cancer survivors.

References