

Recuperating the Lives of Breast Cancer Survivors

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Abstract: Breast cancer is one of the leading causes of cancer deaths among women, second only to lung cancer. Breast cancer treatment and management is done by mastectomy and lumpectomy. Sometimes, radiotherapy is performed after either of the two operations. Following either of the two operations, the breast cancer survivor experiences scars, changes in body shape and symmetry especially if one or two of the breasts were removed. This tends to reduce the survivor's sense of appearance as the survivor feels that she does not fit into the societal notions of idealized female figures. The breast cancer survivor therefore lives in seclusion, confined to their abodes in fear of exposure to the world that would resent their image. This paper is premised on the findings of a study that sought to assess the best possible methods of helping breast cancer survivors live quality life by adjusting faster to their previous life schedule. The study objectives were to determine the physical challenges faced by breast cancer survivors, to assess the breast cancer survivors' awareness needs and counselling strategies for the same, and to develop strategies for improving the lives of breast cancer survivors. The study adopted a descriptive survey design, and used purposive sampling to select four cancer treatment hospitals in Kenya - Kenyatta National Hospital, MP Shah Hospital, Nairobi Hospital and Aga Khan Hospital. The target population constituted breast cancer survivors discharged from the hospitals at least three months before the study. A total of 272 respondents were captured from their respective hospitals as they returned for check-up, and at the hospices where cancer survivors went for support. Questionnaire was the main data collection tool. Data of all categories was tabulated and descriptive statistics used to analyse quantitative data using Statistical Package for Social Sciences (SPSS) version 21.0. The study found that one of the main methods of improving the lives of breast cancer survivors is to provide them with information on how they can improve their body shapes by the use of prosthesis. Their lives can also be improved through financial assistance to purchase new outfits that suit their changed shapes, and by provision of lymphedema sleeve to prevent swellings. This paper, therefore, recommends that cancer treatment hospitals should develop an information bank for providing cancer patients with information regarding the expectation of cancer patients after treatment. In addition, the survivors' family members could provide financial aid which, in turn, will facilitate the recovery process by purchasing new outfits that fit the new body shape of the survivor.

Keywords: Cancer, Survivor, Clothing, Comfort, Concealment, Mastectomy, Lumpectomy

INTRODUCTION

Overview

Breast cancer accounts for 25% of diagnosed cancers, and is the second leading cause of cancer deaths among women after lung cancer in the United States [1]. It is the most recurrent malignancy in women [2]. In Kenya, there are reportedly 39,000 new cases of Cancer each year with more than 37,000 deaths per

year. The leading cancers in women are breast, oesophagus and cervical cancers, respectively. Breast cancer infection rate is estimated at 34 cases per 100,000 women. According to Nairobi Cancer Registry [3], of all the cancers registered, breast cancer accounted for 23.3%, cervical cancer for 20% and prostate cancer for 9.4% [4]. Breast cancer is the most

prevalent cancer among Kenyan women, and constitutes a major public health problem [5].

The most commonly used treatment methods for breast cancer are mastectomy and lumpectomy. The two involve surgical operation around the breast area, and may include partial or complete removal of the breast and the tissues surrounding it, followed by other secondary treatments like radiotherapy. The surgery and accompanying radiotherapy can result in scarring and tenderness, as well as changes to breast size, body configuration and overall torso symmetry [6]. These changes result in changing the shape and general physical appearance of the breast cancer survivors. Since the shape of a female's body defines her general outlook, the results of the operation end up reducing the survivor's self-esteem. Accompanied with other secondary effects like swelling of the arms, loss of hair and other ailments, the surviving breast cancer patient feels that they do not match societal notions of idealized female figures [7]. Consequently, many of them lose hope in life and remain confined to the rooms or homes in fear of exposure to the world. Some of them opt to alter their clothing choices accordingly. They may wear high necklines to cover cleavage in order to present a traditional female aesthetic. Whichever the case, the female feels that she is no longer as adequate as she used to be, and tends to live in isolation, avoiding public places and covers her head. The general situation is that the results of the treatment of breast cancer negatively impact the self-esteem, body image and sexual quality of life because they cannot easily disguise missing or asymmetrical breasts from the public view [8]. Our study, therefore, sought to establish methods of improving the quality of life of breast cancer survivors who are usually in despair due to the changes in their body as a result of the treatment of the disease.

The treatment of breast cancer has major physical impact on the patient with the first physical concern being surgical procedures, followed by drug-enhancing therapies and radiation therapy [9]. Breast cancer survivors experience physical, psychological, behavioural, and biological changes that make them become very sensitive about their bodies and image. This is due to the traumatic and dramatic body changes experienced during the process which, to some extent, trigger negative thoughts and feelings to many of the survivors. Scars from breast cancer surgery and reconstructive breast surgery greatly impact on their mode of dressing, especially since they feel the need to conceal the scars emanating from surgery. Besides, they may no longer fit into their existing clothes previously worn before the onset of cancer. This adds financial aspect onto their misery as they have to seek for new clothes to fit their changed body configuration [10]. They may need specially made clothes to conceal some

of the aftermaths of the surgery. While these may be immediately observable post-surgical challenges, due to the fact that breast cancer disease is not selective and affect any member of society irrespective of her socio-economic status, the disease may pose other more challenges to the recovering BCSs [11]. This study therefore intended to determine the means of lessening this misery.

Purpose, Scope and Limitations

The study, upon whose findings this paper is premised, sought to determine the methods through which some of the life challenges facing breast cancer survivors may be reduced so as to help them adjust faster to their former daily activities. This would, in turn, help them accept their situation thereby improving their life expectancy as they recover their self-worth. The study focused on breast cancer survivors from the four hospitals offering fully fledged cancer treatment in Kenya, namely Kenyatta National Hospital, Nairobi Hospital, Aga Khan Hospital and MP Shah Hospital. The study was limited to BCSs that had been discharged from the target hospitals only; therefore generalizations to those treated in other facilities should be treated with caution. Further, it was limited to breast cancer survivors only and therefore generalizations to other types of cancer survivors can only be done with caution.

The Import of this Work

The discussion in this paper is important since it provides breast cancer survivors and their families with specific methods of lessening the burden of facing new life challenges the survivors find themselves in. As such, family members of breast cancer survivors may benefit from this paper by first of all understanding the predicament in which the breast cancer survivors find themselves after surgery, and then offering solutions as suggested by this study, or come up with homemade alternatives depending on the prevailing circumstances. By so doing, the breast cancer survivor would take a shorter time to accept the reality of the situation, accept their new status and fit in with the society faster than it would have been if they did not receive any help suggested by the discussions herein. It will also help breast cancer survivors themselves to learn that their situation is not unique, but is common to many other breast cancer survivors, and should not therefore despair since others have made it. This is as opposed to a situation where the breast cancer survivor does not get any information about matters surrounding her situation and only knows about herself. Such a person may have a lot of self-pity, a situation that may wear her down and negatively affect her recovery process (even leading to her death).

In addition, this paper benefits the families of breast cancer survivors by pointing out the physical

needs of the survivors in terms of their new outfit as a result of the changed body configuration. They would therefore be more prepared to provide financial assistance to the survivor to shop for a new set of clothes to fit her changed body. Furthermore, this paper is a resource for breast cancer treatment hospitals in their quest to develop policies to create awareness programmes to educate breast cancer survivors about their expectations after surgery, including where to get the right clothes of the right fabric. In this light, fashion designers and tailors may get useful information that can help them develop designs that would fit the requirements of breast cancer survivors with minimal adjustment.

Above all, this paper offers pertinent suggestions in accelerating the recovery process of breast cancer survivors as it would help them accept their situation much faster, follow the recommendations for faster integration with the rest of the population and therefore be able to live more fulfilling lives despite the misfortune of breast cancer attack. Finally, results of this paper inform the apparel industry in meeting needs of breast cancer survivors.

Theoretical Grounding

This study was grounded on the feminism theory. The theory states that females are socialized to approximate social standards of beauty. When the females feel that they do not fit within the social standards of beauty, they tend to develop a negative attitude towards their body and self. Thus, women with mastectomies become more satisfied with their bodies when clothed than when unclothed [12]. The breast cancer survivors are therefore aware of the effect of breast cancer on body image. Accordingly, the breast cancer survivor feels that her body shape becomes lopsided after surgery, and thus becomes secluded as she feels that she no longer fits the societal expectations of a beautiful female.

A feminist approach may help to explain the partners' reaction to support from others. Feminist theory supports the need for reaching out for help beyond the family level. The theory also helps explain partners' experience of their wives' breast cancer. Breast cancer affects the survivor's partners as much as the survivors themselves. However, one cultural standard of male socialization is that men do not express their feelings, particularly more vulnerable ones such as fear and sadness [13]. Partners find difficulty in explaining their experiences in the wake of breast cancer. The difficulty could be attributed to male gender role socialization, which describes a man as strong and able to withstand any situation courageously. Since breast cancer in a partner has several weak areas, the male hesitates to describe these areas of weaknesses.

The study deemed this theory applicable as it shows the predicament of the breast cancer survivor as she tries to resume her daily activities following the surgery. The study shows the struggle associated with a female losing her breast(s), coupled with her need to fit into the society that has specific understandings of the female body appearance. The struggle cannot be solved through performing anything in an instant, but needs patience and understanding from the partner.

Literature Review

Treatment for breast cancer creates a struggle with fit, comfort and aesthetic concerns related to apparel post-surgery [10]. Although there are many common concerns with post-mastectomy women, the different psychosocial stages are uniquely experienced by post-mastectomy women. This unique path influences the clothing needs and desires of breast cancer survivors as they cope with lifestyle demands and try to find some sense of control to take a more active role in what is impacting their lives.

Clothing attributes play an important function for the post-mastectomy woman as fit, fabrication and comfort play important roles in appearance management [14]. The consideration of a clothing item's fit begins when the garment style is selected. The elements of design that include line and colour combine to create the visual and structural fit of the garment. Line can lengthen (vertical), shorten (horizontal), or shorten and widen (diagonal) and thus work with figure variations to disguise irregularities and lead the eye up to focus attention on facial features rather than the area of breast amputation [11].

According to Beard [9], clothing needs to move with the body and care needs to be taken not to constrain the chest wall where surgery has occurred, or the arm on the surgical side with oedema concerns. Thus, the selection of fit, style and bodices are important considerations. The garment profile and type of fabric control the amount of ease that is allowed for movement and overall fit. While fabric selection is not critical to the fit of a garment, the addition of a stretch fibre such as Lycra can alter the amount of ease offered by the garment and influence how closely it clings to the body. Early post-mastectomy women may need to protect surgical incisions, contend with skin irritations from radiation, and counter post mastectomy pain discomfort [10].

Breast cancer survivors need information regarding various aspects of cancer treatment and recovery process. According to Gregor [15], patient education has been seen as a nursing function from the earliest days of the profession. For the last 35 years in nursing, patient teaching has been the subject of substantial discourse in the nursing profession with

usage of descriptive terms such as systematic, rational, well planned, and nursing controlled. Patient education is considered an important aspect of patient care and is related to patient satisfaction, healthcare provider performance, and clinical outcomes [16, 17]. Patients today are discharged from the hospital quickly as hospitals strive to have efficient utilization of their services with the shortest length of stay, which challenges healthcare professionals to provide consistent high-quality care [18].

Surgical treatment for breast cancer includes both breast conserving and non-breast conserving modalities [9]. Breast conserving treatment includes lumpectomy, an operation in which the breast lump, along with a portion of the normal tissue around it, is removed. This type of surgery is often followed by radiation treatment and/or chemotherapy with its accompanying hair loss. Another operation that is breast conserving is partial (segmental) mastectomy (quadrantectomy), in which more of the breast tissue is removed and again possibly followed by radiation therapy and chemotherapy. Non-breast conserving surgical treatment includes simple mastectomy, in which the total breast is removed but does not include the lymph nodes under the arm or the muscle tissue beneath the breast itself. One or both breasts may be removed. Modified radical mastectomy is an operation in which the entire breast is removed along with some of the lymph nodes under the arm. This is the most common when the whole breast is being removed. Radical mastectomy occurs when the removal is extensive and includes the entire breast, lymph nodes and the chest wall muscles under the breast [19]. Non-breast conserving surgeries may be followed by radiation therapy and chemotherapy.

In order for retailers to maintain good market performance, the customer should be served in a manner to attain customer loyalty. In order to attract and retain breast cancer survivors as customers, the retailing environment should be suitable for one of their newly acquired basic needs: the need to privacy that enables concealment of scars resulting from the effects of breast cancer surgery. According to Ghosh, Tripathi

and Kumar [20], it is very important that, for retailers to continue to garner customer loyalty, the retailers should continually respond to the demands of the consumers. 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 [21]. This increased number of breast cancer survivors forms a large target group that entrepreneurs can reap heavily from. But this is only possible if the entrepreneurs can provide them with the services they need – a suitable fitting room setting that allows for accurate dimension measurements while, at the same time, does not allow for exposure of their surgical scars to the rest of the public.

MATERIALS AND METHODS

The study adopted a descriptive survey design. The target population constituted breast cancer survivors discharged from four cancer management hospitals in Nairobi (KNH, MP Shah, Nairobi and Aga Khan Hospitals) at least three months before the study. Individual respondents were captured from their respective hospitals as they returned for check-up and at the hospices where cancer survivors go for support. Questionnaire was the main data collection tool. Data of all categories was tabulated and descriptive statistics used to analyse quantitative data using Statistical Package for Social Sciences (SPSS) version 21.0 [22]. Results of the study gave rise to the recommendations on how to help breast cancer survivors live quality life after surgery.

The study was carried out in selected hospitals in Nairobi in view of the fact that hospitals with full capacity for cancer treatment are all concentrated in Nairobi. These were KNH, MP Shah, Nairobi and Aga Khan Hospitals. Three out of the four hospitals provide psycho-social support to their patients, while all of them have established linkages with hospices.

RESULTS

One of the physical challenges facing BCSs was swelling of arms and hands. It was found that 16% of respondents experienced this challenge as presented in Figure 1.

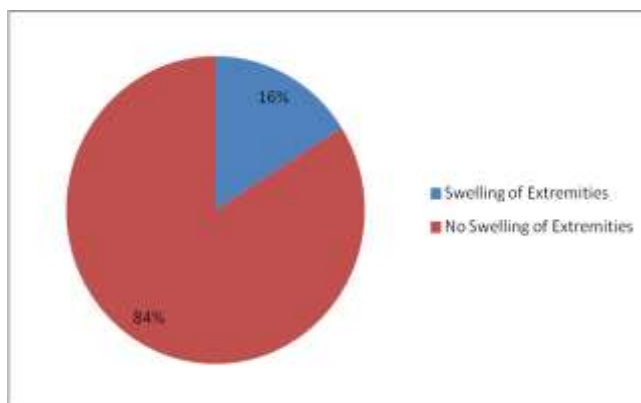


Fig-1: Proportion Experiencing Swelling of Extremities

The swelling is controlled by the use of lymphedema sleeve. However, only 38% of them used the sleeve. It was also found that the patients lacked shape due to the absence of one or both breasts,

removed as a treatment procedure (mastectomy and lumpectomy). The clothes earlier used by the breast cancer survivor would not fit due to the change in the bust area, as depicted in Table 1.

Table-1: Proportion of Survivors Using Previous Clothes

Clothes use situation	Number of respondents (f)	Respondent proportion (%)
Those not using previous clothes	223	89.9
Those using previous clothes	25	10.1
Total	248	100

Respondents who were not using previous clothes had various reasons for not doing. These reasons are expressed in Table 2.

Table-2: Reasons for Not Using Previous Clothes

Reason	Number of respondents (f) (N=223)	Proportion (%)
Bust area too loose	203	91
Tight on the arms	45	20.2
Clothes were sensitive to body	94	42.2
Gave poor body shape	182	81.6

From Table 2, it is clear that previous clothes were loose in the bust area when worn by breast cancer survivors due to the removal of one or both breasts and the resultant poor shape of the breast cancer survivors were the key reasons for the breast cancer survivors not being able to use their previous clothes. To overcome the predicament of poor shape and looseness of previous clothes in the bust area, breast prosthesis can be used to replace the lost breast. This would help the

survivor recover the lost bust shape and help regain general body configuration. However, it requires financial backing.

Breast cancer survivors were also found to experience numbness on the affected part, swelling of arm on the affected side, skin tenderness, loss of body heat regulation and generally sensitive skin, as depicted in Figure 2.

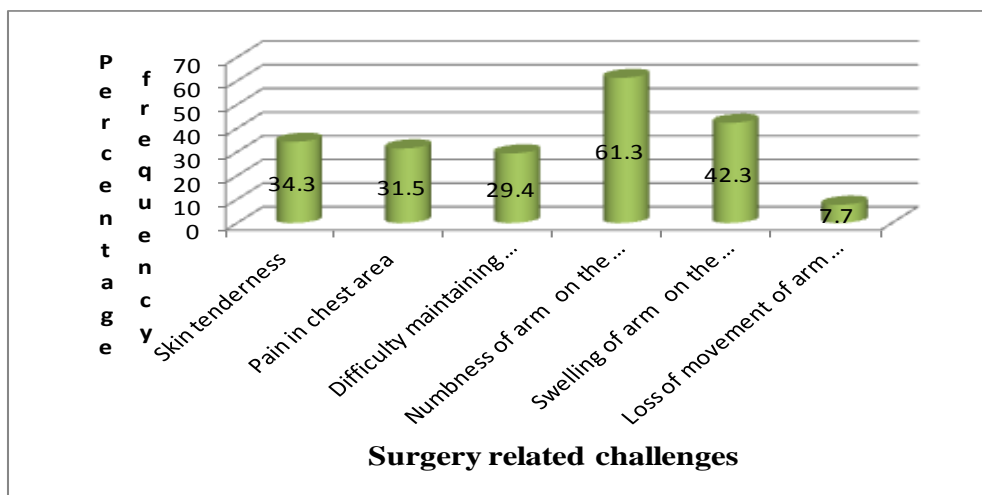


Fig-2: Surgery-Related Challenges

This implies that the breast cancer survivors cannot just use any cloth fabric but specific fabrics that are comfortable for their skins. The clothing fabric must be soft enough and not sensitive to her tender skin, be elastic to a little extent so as to make it easy to wear without much straining.

Breast cancer survivors faced the problem of trying out clothes to find the most fitting. Due to their need to conceal parts of the body that would not be a problem to any other woman, the survivors resent fitting clothes in relative publicity like in the shop where there are other shoppers. They therefore need a secluded fitting room that is fitted with mirrors to

enable them view most parts of their body. This implies that clothes retailers should have a secluded room fitted with mirrors to suit the needs of breast cancer survivors.

The study found that majority of breast cancer survivors did not get any information from the medical staff prior to surgery or at discharge about the challenges they expect to face following surgery. They therefore lived on a try-and-error mode and discovered things as they happened to them. It was found that breast cancer survivors need information concerning bras for prosthesis. The nature of awareness that breast cancer survivors needed is presented in Figure 3.

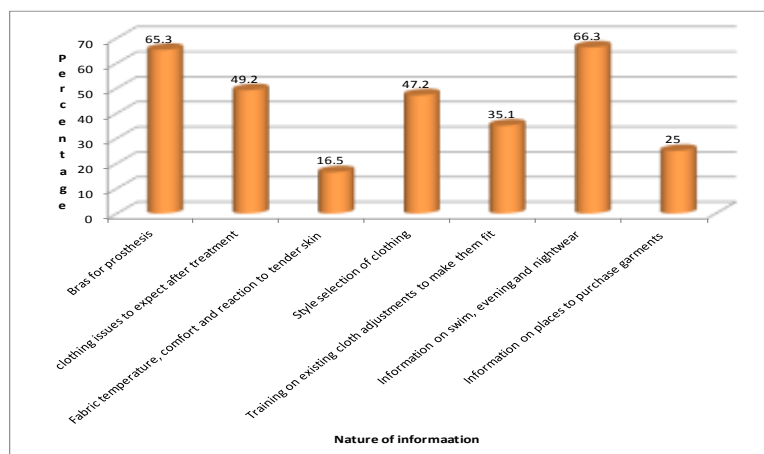


Fig-3: The Nature of Information Breast Cancer Survivors Need to Know

Since the first major physical effect of surgery was the loss of shape due to the removal of breasts, the most important information the survivors needed was how to recover the lost shape. This is done by the use of prosthesis and hence this is the first information they would like to be furnished with.

Breast cancer survivors would also like to get information on the clothing issues to expect. This is because the breast cancer survivor's concern after the life challenging ailment is covering the effects of the treatment. They thus would like information regarding clothes they would wear to cover the effects.

The results of the study compare closely with results from previous studies. For instance, a study by Jeziorski *et al.* [23] found that after surgery, the remaining body configuration varies by the type of surgery and the closure technique that was used, thereby affecting the survivors' clothing needs. Golshan and Smith [24] reiterated that the procedures used to treat breast cancer leave perceptible changes within the body, including lymphedema with resultant swelling of the arm, loss of body heat regulation, reduced mobility of upper limbs and torso, skin sensitivities and early onset of menopause. All these affected the clothing needs of the survivors. Rasband and Liechty [11] add that the right design work with figure variations to disguise irregularities and lead the eye up to focus attention on facial features rather than the area of breast amputation, thus helping in hiding the areas that may have been affected by surgery. A study by Jackson [10] found that one of the key clothing concerns among participants was information regarding bras for prosthesis. Thus, information regarding the use of breast prosthesis is very crucial to the breast cancer survivors. The current study had a similar result to the study by Jackson [10].

DISCUSSION

Females are generally very concerned about their external appearance. As such, anything interfering with a female's appearance greatly hurts the concerned female. The occurrence of breast cancer and its treatment greatly interferes with her shape, reduces her self-esteem and personal outlook. Recovery from breast cancer involves more than the physical recovery, but acceptance of her body as it appears following surgery takes a great deal of the process. In fact, the person may not regain her normal daily operations before self-acceptance.

Clothing is one of the items that can help the breast cancer survivor to accept oneself and thereby accelerate the physical recovery and resumption of daily activities that she used to perform before cancer attack and subsequent mastectomy. But this is only possible if the clothes that the survivor wears covers the parts she would like covered, gives her some semblance of shape comparable to her former self, and is comfortable to her. This calls for the design of clothes that can fit all these bills. One of the first elements of concern is the replacement of the amputated breasts, albeit through provision of artificial ones. This calls for the provision of prosthesis either separately with a place to fit into in the cloth designed for such a person, or the inclusion of the prosthesis in the cloth designed for the recovering survivor. This would help the survivor to recover both psychologically and physically, a situation that would help the person to regain her initial self-worth. Thus, it is important that the right cloth is designed for breast cancer survivors since the cloth

would not only perform its normal function of covering the body, but would also play a role in helping the survivor regain her self-esteem, thereby resume her normal chores as she used to before surgery.

CONCLUSION

From the foregoing, it is clear that breast cancer survivors encounter a number of challenges following their life saving surgery. It takes quite some time for them to recover and start performing their duties as they used to before the onset of cancer. During this period, they are faced with secondary ailments emanating from the effect of the treatment and, above all, they are concerned about their self-image among their peers or people they meet regularly. They avoid being seen in public and would like to conceal most parts of the body that have scars created during surgery. However, the breast cancer survivors can be assisted to fully recover from the effects through a concerted effort of friends and relatives. Since the survivors may not have financial capacity to provide for themselves whatever they need as they may not have been involved in any economic activity, it is important that she gets such kind of assistance. They may also need specific clothing material that would not necessarily be among the clothes she used before. This calls for the purchase of a new outfit, an undertaking that calls for funds. In general, breast cancer survivors need moral, financial and material support to overcome the effects of the aftermath of surgery. The provision of any of these would help them accept their situation and adapt to the new way of life faster and thereby increase their life expectancy.

RECOMMENDATIONS

Breast cancer survivors need breast prosthesis to help them regain their shape. They should therefore be helped to acquire it in case their financial situation does not allow them to acquire it. This helps them to gain self-confidence as it restores the distorted bust area as a result of the surgery.

Breast cancer survivors should use fabrics that do not irritate sensitive skin. This implies that clothes with scratchy lace or elastic should be avoided as much as possible. The main clothing fabric for breast cancer survivors should constitute cotton due to its comfort and absorbency.

Clothes stores and retailers should have secluded fitting rooms that can be used by breast cancer survivors to try out clothes before buying. The room should be fitted with mirrors to enable them view themselves as they do not want other people to act as their mirrors as they do not want to expose the scarred areas of their body.

Breast cancer survivors should be given information about what they expect to encounter just before release from the hospital. This would help them be more psychologically prepared to face the world. Specifically, they should be advised about how to regain body shape, how to conceal the scars and other information related to their illness. This would help them regain self-esteem as they will know that their situation is not unique.

Breast cancer treatment hospitals should start a clothing store that would stock the items required by breast cancer survivors immediately after discharge. These include bras for prosthesis, lymphedema sleeve and anything else that the survivor would require immediately following discharge. This would come in handy as the patients would be in a position to acquire them as their need arises.

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