

Experiences of Female Breast Cancer Survivors on their Appearance Related Issues Impacting their Identity

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Abstract- When women diagnosed with breast cancer undergo mastectomy and adjuvant medical treatment, they are confronted with multiple side-effects causing appearance related issues that have a profound impact on their identity, implicitly in terms of their sense of self and explicitly in terms of their social self. Therefore the aim of the study was to explore how the altered appearance of female breast cancer survivors impacted their perception of self-identity, after undergoing mastectomy and adjuvant treatment. The objectives of the study were - a) to explore the concept of physical appearance among female breast cancer survivors and b) to explore the issues faced by female breast cancer survivors in relation to their physical appearance. The sample included 7 female breast cancer survivors selected from a purposive non-probability sampling technique. They were interviewed based on a semi-structured interview guide. The data transcribed was analyzed using directed content analysis. The findings involved two global themes-1) Concept of physical appearance-survivor's perspective and 2) Problem adoption and adaptation-indicating the identity stability. Through these results the present study concluded that altered appearance of female breast cancer survivors impacts their perception of self-identity, in the explicit perspective more than the implicit perspective, after undergoing mastectomy and related treatment.

Index Terms- Breast cancer, Survivors, Appearance, Identity

I. INTRODUCTION

Breast cancer is a serious condition where malignant or cancerous growth of cells affects the tissues of the breast. Breast cancer has become a common condition with a rise in the diagnoses of new cases along with an increase in the survivorship. Although survivorship has increased, such a health condition is associated with multiple changes in one's perception of their identity due to the many appearance related issues they are confronted with during the treatment process (Kaiser, 2008). A large number of them face immense emotional distress due to appearance related issues that alter perceptions of who they are, demonstrating the need for psychosocial therapy, counseling and support (Mehnert & Koch, 2007).

II. CONCEPT OF PHYSICAL APPEARANCE

Physical appearance is viewed synonymously with the concept of physical attractiveness. With this similarity stereotypical meanings have been indicated by studies that conclude physically attractive people are more sociable, physically and mentally healthier, sexually exciting, and more

successful in their future and present tasks (Patzer, 2006). With the attribution of such significance to physical appearance, physical alterations usually decrease physical and mental quality of life, causing female breast cancer survivors to have feelings of low self-concept (Lloyd et al., 2000). Appearance related issues among breast cancer patients mainly arise from the traumatic surgical and adjuvant treatment period that they go through. The surgical option of mastectomy, involving removal of the entire breast leads to severe physical and mental stress to the individual undergoing the procedure as it is difficult for them to imagine a disfigured asymmetrical structure of the body (Frith, Harcourt & Fussell, 2007). Along with mastectomy, chemotherapy and radiotherapy are also administered as adjuvant techniques that are explained as traumatic due to their side effects on the physicality of the individuals. They alter the physical appearance by bringing about- changes in weight, discoloration of skin, fingers and toe nails, loss of hair, dark circles surrounding eyes, vaginal dryness and infections, chronic fatigue (Bertero & Wilmoth, 2007). These negative consequences adversely affect their psychological coping in a dire manner (Harcourt & Frith, 2008). It has been observed that appearance related changes often lead to an altered sense of self, psychological depression, insomnia and feelings of shame that significantly affect their self-confidence and general well-being in comparison to pre-morbid levels of functioning (Bower, 2008).

III. IDENTITY

Identity as a concept has been derived mainly from the works of the psychologist Erik Erikson in the 1950s (Erikson, 1968). Commonly used formulation to define identity has been seen in terms of how a person defines who he or she is or in other words self-definition or self-understanding, which is too broad, vague and ambiguous. It is a multi-dimensional concept that has generally been defined by the complex question, "Who am I?" that involves an integrated image of oneself as a unique person, therefore distinguishing them from others who hold and value different beliefs (Bernstein, Alison, Roy, Srull & Wickens, 1994). When an individual is dissatisfied with one's uniqueness or differences in their outer appearance, there is a lesser integrated identity.

Self- identity is an enduring concept that has evolved over the years through various life experiences that involve the interaction of one's own nature with the external environment, building a system of values, cherishing feelings of worth and certain prized material aspirations. It is strongly influenced by feedback received from the outside world that can include spiritual beliefs, intimate relationships, family and peer support,

and other societal agencies (Bailey, 2003). Thus identity can be explained using a dual perspective that includes self-understanding and societal understanding of oneself. Viewing as a whole, the present study views identity as either a) 'a social group defined by certain membership rules and supposed characteristic attributes or likely behaviors', and b) 'socially differentiating features that a person is proud about and those that are unique of an individual, therefore viewing them as relatively stable but socially influential' (Fearon, 1999). This provides an understanding of identity in its entirety with a socially defined perspective (explicit identity) integrated with a personal perspective (implicit identity). An interaction of the two perspectives influences the perception of one's physicality.

IV. MAJOR AIM

Largely, the present study strived to explore how the altered appearance of female breast cancer survivors impacted their perception of self-identity, after undergoing mastectomy and further treatment.

V. OBJECTIVES

1. To explore the concept of physical appearance among female breast cancer survivors.
2. To explore the problems faced by female breast cancer survivors in relation to their physical appearance to understand the stability of their identity in the face of bodily alterations.

The larger aim connected to the specific objectives stated above together were fulfilled by observing the experiences of women who have undergone breast cancer treatment therefore shedding light on the personal perception of their physical appearance impacting their sense of self, connection and identity (Rosedale, 2009).

VI. METHOD

An interpretive phenomenological research design was employed to study the experiences of female breast cancer survivors on their appearance related issues. The study employed a qualitative descriptive research method.

For the purpose of the study the population consisted of all female breast cancer survivors who had undergone treatment for the disease. A non-probability purposive sampling technique was employed for the study to select 7 female breast cancer survivors who had undergone mastectomy and were undergoing further treatment since a minimum period of six months after the surgery from an oncology center in Karnataka, India. The selection

criteria involved married female breast cancer survivors within the age range of 30 to 50 years who had undergone mastectomy and had continued treatment for a minimum period of six months to a maximum of one year after mastectomy. Those who were considered as participants were finalized after receiving consent from them. The participants were made aware that they had the freedom and the right to withdraw from the study without any obligation to the researcher or the study they agreed to participate in. Those participants who were willing to participate in the study were interviewed using in-depth interviews for a period of 30-50 minutes. The interview process was led by a semi-structured guide consisting of open-ended questions that were framed along with the usage of probes to aid the participants in eliciting elaborative responses about any appearance related issues if present and how that affected their identity. The guide consisted of 20 questions with multiple sub-questions, and they were organized according to the specific objectives that fulfill the major aim. Following this the interview guide was sent to three subject matter experts who have knowledge in the field of clinical psychology and cancer related issues to acquire various suggestions and perspectives for the improvisation of the guide. The interviews were conducted and audio-taped after which they were transcribed into text format for further analysis. All data collected was kept confidential.

The data collected was interpreted and analyzed using qualitative directed content analysis because there has been prior work conducted in the field and the goal was to widen and explore the experiences of the population (Hseih & Shannon, 2005).

VII. RESULTS

The socio-demographic data obtained revealed that the seven female breast cancer survivors had a mean age of 40.71 years. Majority participants belonged to urban backgrounds, having joint families as their support systems, where their roles included managing the entire household with some of the participants balancing work life and personal life.

There were two global themes recognized in relation to the two specific objectives considered. Based on the ascertained coding framework that utilizes specific meaningful segments (lines in paragraphs) of text or refined data as determinants for the formulation of themes, the following were the themes arrived at-

1. Concept of physical appearance- Survivors' perspective
2. Problem espousment and adaptation- Understanding the identity stability

Table I: Themes Obtained from the Present Study

Global themes	Organizing themes	Basic themes
1. Concept of physical appearance	1a. Perceived description of physical appearance : survivor’s perspective	i. Physical appearance observed from an overt viewpoint
		ii. Stereotypical indicators of good physical appearance
		iii. Indicator of a healthy individual
	1b. Perceived importance of physical appearance in their lived experiences	i. Significance of physical appearance in their lives
		ii. Physical appearance is incongruent to perceived contentment and life satisfaction
2. Problem espousment and adaptation	2a. Shift in perceived sense of self-identity	i. Encounter with disfigured bodily conditions
		ii. Redefinition of explicit identity
		iii. Redefinition of implicit identity
	2b. Resilience	i. Experiential learning
		ii. Self growth

1. Concept of physical appearance.

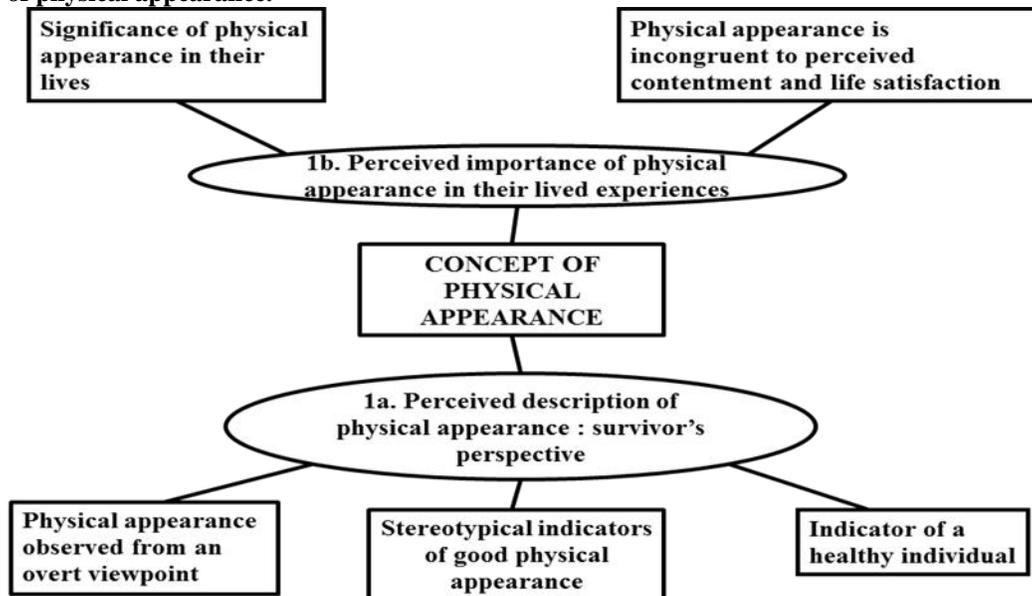


Figure 1:Network of Theme 1

The survivors understood physical appearance as being determined by how a person looks based on certain stereotypical indicators such as the kind of hair, skin color, body size and fitness and similar ones. It was perceived as sometimes determining a person's inner qualities and their nature, which is not necessarily true of the person. Therefore in the survivors' opinion physical appearance should be perceived as something existing at a very surface level that cannot be considered as a determinant judge of the inner appearance. Identity was attributed as being maintained more by the individual's inner self and the family support existing, rather than anything related to the physical appearance. Stability of identity was observed to be merely related to appearance.

1a. Perceived description of physical appearance: survivor's perspective.

- i. Physical appearance observed from an overt viewpoint
- ii. Stereotypical indicators of good physical appearance
- iii. Indicator of a healthy individual

Physical appearance according to the female breast cancer survivors was described in terms of how they view it and what they believe is the meaning of physical appearance. Differing thoughts following the same thread were observed to be consistent regarding some basic themes like, physical appearance being observed from an overt point of view. Appearance was considered as something reflected through the mirror and through a social point of view, indicating the social influence on

individual's beliefs and assumptions therefore affecting the personal understanding of physical appearance. The stereotypical indicators for good physical appearance were pointed as looking physically normal, healthy and ideally beautiful with black hair, fair and clear skin, and a likeable bodily figure.

1b. Perceived importance of physical appearance in their lived experiences.

- i. Significance of physical appearance in their lives
- ii. Physical appearance is incongruent to perceived contentment and life satisfaction

The survivors' agreed that there were certain stereotypical indicators describing good physical appearance. However, they disagreed about attributing major importance to such indicators. Combating and surviving a fatal illness had instilled a sense of understanding about the importance of life among these survivors compared to any other healthy persons. As they would have experienced a life with breast cancer the significance of a life without disease was much greater than attributing any importance to physical alterations caused by the surgery and treatment. Although most participants felt glad about surviving, few of the survivors did experience some sadness related to their lost beauty mostly during a social event or among other people. On another tangent, physical appearance was perceived as important to lead a healthy life rather than to look good.

2. Problem espousment and adaptation.

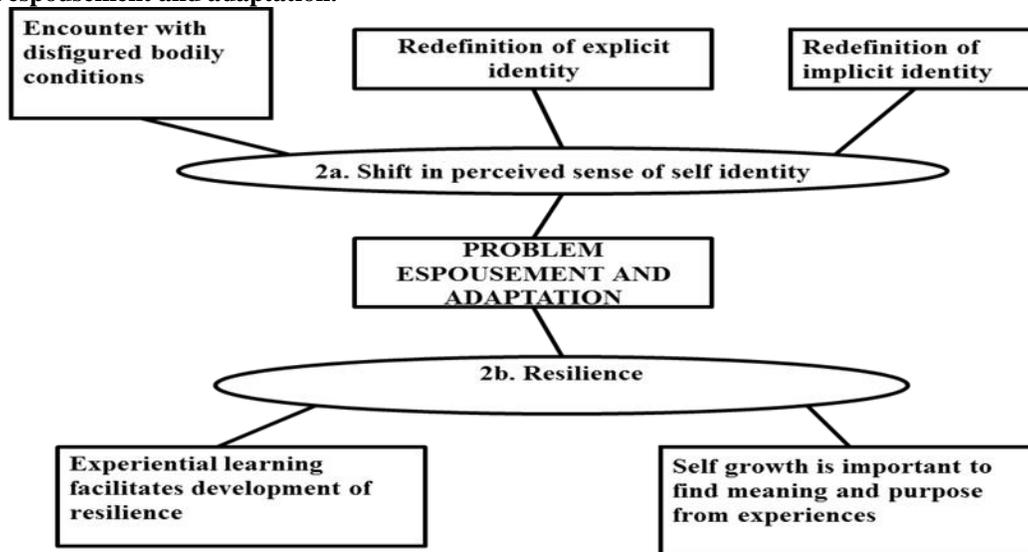


Figure 2: Network of theme 2

Female breast cancer survivors were found to have confronted various issues related to physical appearance in a rather intrepid manner. They had experienced distinct bodily changes due to the process of cancer treatment which had varying effects on their perception of the stability in identity. The problems observed by all of them were distorted bodily figure, loss of hair, darkening of the skin around the eyes, drying of the skin and other many issues. Although these bodily alterations were difficult for them to accept, most survivors strongly emphasized on striving to accept and adapt to the alternate bodily appearance by dealing resiliently with the impact created by these problems on their personal or implicit self and social or explicit self. Various themes delineated here explore the stability in the maintenance of identity from their previous healthy self to their present self where the survivors in their best endeavors have championed these problems.

2a. Shift in perceived sense of self-identity.

- i. Encounter with disfigured bodily conditions
- ii. Redefinition of implicit identity (personal identity)
- iii. Redefinition of explicit identity (social identity)

Perceived sense of who they are and how they perceive the society's attitude towards them were seen to be at varying levels. Emphasizing on the problems faced in line with the appearance related changes; all survivors had confronted similar issues due to the same surgical procedure and the further treatment process. These changes had impacted them in latent or manifest ways in the manner of perceiving their social identity in a rather different manner compared to the maintenance of stability in terms of their personal identity. Simply explaining, the considered survivors showed some inhibition accepting their physical changes while facing the social environment. They had no inhibitions when in a protected positive family environment. An interesting aspect is that although there was a clear expression from most survivors of being the same as before in terms of personal identity given satisfied support from their family, these appearance related issues seem to have affected their social identity as they feel the need to conceal their cancer affected physical changes to obtain

the same social reaction and feedback from the others in their environment like before.

2b. Resilience.

- i) Experiential learning
- ii) Self growth

Resilience derived from various sources was found to be dominant across themes although in varying ways. When describing the problems related to physical changes also observed were the ways in which these appearance related issues had impacted their identity. Altered bodily changes were found to have impacted their social or explicit identity in a more profound manner rather than their implicit identity requiring them to maintain their cancer appearance in a covert manner. Learning to deal with social experiences and other life experiences in a covert and mentally confrontative manner, they became more resilient and developed individually in various ways.

Resilience within an individual does not always have to be developed because of social experiences from the environment. Certain experiences from within that are inclusive of personality traits of certain individuals also seemed to contribute towards resilience and self-growth. Many participants indicated growing through life experiences during the crisis situation of their cancer appearance. Optimism seems to be very evidently portrayed spelling out resilience for them. Resilience was found to develop while confronted with cancer experience, by believing in individual strength, confidence and unchanging personality prioritizing the unseen future rather than ruminating about the past. Another resilient quality was the belief of being a woman with inner beauty ignoring any appearance related issues. Contrasting to these findings of positive resilience one of the participants expressed a lot of pain about how a woman is viewed negatively by being considered a bad omen after undergoing bodily alterations. This indicates that resilience is subjective to the individual and requires a balance of internal and external support from the society and family to maintain a stable

identity therefore dealing effectively with appearance related problems.

VIII. DISCUSSION

Conceptually, identity was viewed in the forms of explicit and implicit types that were influenced from various factors including inner and outer appearance, interpersonal relations, social relations, resilience and emotional or psychological well-being. These factors observed are very important in the face of appearance related changes impacting identity. The themes discussed therefore indicate the presence of these factors in their experiences.

The first theme observed was the 'Concept of physical appearance from the survivors' perspective' in general terms and in specific terms from their lived experiences. In specific terms they explained the perceived importance of the general concept in their own lives. It was found that although survivors observed physical appearance as overt, marked by stereotypical indicators, appreciated by social others and that which is attractive, when it came to perceived significance in their own lives, they did not attribute much value to it in their lives. They preferred surviving a healthy life regardless of the physical changes in themselves. In contrast to the present finding, most previous studies have found that female breast cancer survivors perceive the concept of physical appearance as playing an important role in their well-being. A study focusing on body image among young female breast cancer survivors aged below 50 years found a contrasting result to the present finding. It was observed that a substantial population of women in their early months of diagnosis undergo crisis related to body image as they attribute significant importance to physical appearance in their lives. Most sexually active women, wished for good physical appearance in their lives, although due to mastectomy associated issues it could not be fulfilled (Fobair et al., 2006). In disagreement with most previous studies one of the few studies concluded with a similar idea as the present finding. They found that psychosocial disturbances were greater compared to any disfigurement or sexuality related issues and that these were in minimal significance compared to their health. As a fact, they reported that greater concerns like needs for emotional, psychological and social support were considered more valuable predictors of psychosocial health and positive outcome (Khan, Bahadur, Agarwal, Sehgal & Das, 2010). Observing that the present study agreed to this finding it is important to explore the reasons behind differences in the perceived importance of physical appearance.

The reasons can be culture oriented, understanding of the concept of self in their lives, level of responsibility, level of emotional and family support and level of acceptance by the immediate family members. A collectivistic-culture orientated study found that positive immediate support facilitated the survivors to think beyond their physical loss and strengthened their mental well-being, making them stronger within themselves (Muhamad, Afshari & Kazilan, 2011). Another factor about prioritizing health and family over appearance to balance a stable identity can be observed due to the responsibilities an Indian woman feels obligated towards in a committed manner. This was also expressed by a survivor in the present study about how

women can undergo an altered appearance and still get back to normal routine adapting in the best manner possible. A study observed that traditional cultural narratives explain women as expected to stabilize home and family, and portray unconditional self-sacrifice and nurturance (Mudita & Paul, 2006). Therefore, these women survivors prioritize their life over family and their duties rather than being preoccupied with their appearance related issues.

The second theme was termed problem espousement and adaptation. The present study explored the various problems that the survivors face, ranging from physical changes in their body and severe pain and fatigue to confronting the social others who express unnecessary sympathy. These issues were found to influence the survivors in redefining their sense of identity especially in terms of their social self, causing them to maintain a secretive identity of their disease and appearance related changes. They redefined their social self to feel comfortable interacting normally with the social others. Their personal identity was seen to be stable despite appearance related issues due to the immediate family support and care received from the family along with their individual enduring personalities. Majority participants did not feel the need to use prosthesis to cover their physical loss. They felt a sense of growth from their cancer experiences and therefore felt an overall sense of resilience and movement in their self-identity. The survivors accepted and adopted the problems associated with breast cancer and adapted to them in a positive manner. One of the studies that agreed with the present finding through qualitative multiple case study explored the posttraumatic growth from breast cancer. It was found that challenging life events potentiate personal growth and aid the survivors in comprehending such events as a learning enhancing the process of growth. Supporting the present finding it was found that survivors confronted the issues by enduring crisis, coping with changes and engaging mentally by adapting to various consequences, therefore adjusting to their normal selves. Therefore, adopting positive perspectives and adjusting oneself to alterations are keys for self-growth (Hoggan, 2011).

Another study supports the present finding that the perspective or the lens used to view the problems, and adopt the problems determined the extent of adaptation. It was found that subjective perception of stressful events and personal diathesis seemed to be strong predictors of posttraumatic growth. Other important factors determining adaptation to cancer related problems were contextual factors, resilience hardiness and cognitive appraisal (Gallagher-Ross, 2011). Similarly a study exploring the process of survivorship explained that they undergo an identity reformulation process to adjust to a new lifestyle and employ creative problems solving strategies to alleviate prolonged distress and bridge the discontinuity between their past, current and ideal selves. This marked the survivor's overall well-being (Sherman, Rosedale & Harber, 2012).

These findings aid the present observations in stating that problems associated with breast cancer are several in terms of not only physical alteration of self but also social nature of self influenced by the way others perceive you. Therefore individual redefinition and adaptation of self is subjective and is important to become more resilient towards these experiences and to grow as an individual. An interesting observation was that most research published concentrates on vague concepts of self and

identity which is difficult to be used for evidence based intervention as the focus is very large. A finding such as the one in the present study explains what are the various problems and moves on to explore to what extent social identity and personal identity undergo a change due to the appearance related problems a directed manner.

IX. CONCLUSIONS

The two global themes obtained fulfill the larger aim ascertained by fulfilling the two specific objectives laid out. The first objective was to explore the concept of physical appearance among female breast cancer survivors. This was fulfilled by the observation of theme 01 which is 'Concept of physical appearance', that explained the significance attributed by the survivors to the concept of physical appearance from their lived experiences based on their general understanding of the concept. The second objective was to explore the problems faced by female breast cancer survivors in relation to their physical appearance. This was fulfilled by exploring the various appearance related issues and adaptation to these issues through understanding theme 02 that is 'Problem espousement and adaptation'. The theme also explained self growth and resilience developed through experiential learning. Therefore, fulfilling the major aim the present study established that altered appearance of female breast cancer survivors impacts their perception of self-identity, in the explicit perspective more than the implicit perspective, after undergoing mastectomy and adjuvant treatment. Explicit identity was observed to play an overarching factor on survivor adjustment and personal identity. To understand the survivors' way of coping and maintaining a stable identity further studies would be required. Additionally, future studies emphasizing on the socio-economic strata & cultural factors that greatly influence psycho-social adjustment of individual identity would also need to be executed to analyze survivors experiences further..

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