

## Experience of the Young Women with Early Stage Breast Cancer: A Qualitative Study

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### ABSTRACT

The cells in the breast begin to grow out of control is called as breast cancer. This is classified into stage zero to stage four according to the amount of severity and nature of spread. During early stage, diagnosis of the cancer and beginning of treatments are directly affected to quality of life of the young women. Most of women have unpleasant physical, psychological, and sociocultural experience due to impairments and functional limitation secondary to breast cancer. Purpose is to explore the experience of the young women with early stage breast cancer at oncology unit in Provincial General Hospital Kurunegala. A phenomenological design was carried out to explore the experience of young women with early stage of breast cancer. Twenty participants were purposively selected diagnosed with breast cancer within 3 to 6 months, who are attending to the oncology unit at Provincial General Hospital Kurunegala. Ethical approval was obtained from the Ethics Review Committee of the same hospital. Semi-structured interviews were conducted to collect data and thematic analyze was used for the analysis. Three major themes were derived from the data. Major themes are severe physical discomfort due to disease condition, emotional disturbances and impaired socio-economic life. Severe physical discomfort is commonly due to pain, loss of appetite and nausea, body image changes and barriers to day to day activities. Emotional disturbances mostly have seen as a result of depression, anxiety, fear of recurrence and uncertainty about life. Lack of family support, social support and decline economic status were affected to impaired socio-economic life. It is concluded that pain was the mostly

faced discomfort. Anxiety and depression have seen in high extent once they heard about the disease condition and after. Patients suffered a lot as decline their economic status because of left the job and frequent hospitalizations. All these experiences collectively affect to the quality of life in early stage breast cancer patients. Hence, it is recommended to educate the patients about the coping mechanisms in advance.

**Keywords:** early stage breast cancer, young women, mental status, oncology clinic, severe discomfort and socio-economic life

### INTRODUCTION

Breast cancer is the most prevailing cancer in women as well as the second most common cancer reported overall in the world. <sup>[1]</sup> There were over 2 million new cases were reported in 2018. <sup>[2]</sup> There will be an estimated 18.1 million new cancer cases (17.0 million excluding nonmelanoma skin cancer) and 9.6 million cancer deaths (9.5 million excluding nonmelanoma skin cancer) in 2018. In both sexes combined, lung cancer is the most commonly diagnosed cancer (11.6% of the total cases) and the leading cause of cancer death (18.4% of the total cancer deaths), closely followed by female breast cancer (11.6%). Around the world, breast cancer now represents one in four of all cancers in women. <sup>[3]</sup> Cases of invasive breast cancer and survival rates range from 40% in low income countries to more than 80% in other countries. <sup>[4]</sup> Thus, it will become a major

health burden both in developed and developing countries.

Breast cancer has been known to mankind since ancient time. [5] It is divided into stage zero to stage four according to the amount of the spread and the nature of the spread. [6] Among them, fourth stage breast cancer is extended beyond the immediate region of the tumor and may have invaded nearby lymph nodes of distant organs. When patient diagnosed with fourth stage breast cancer, they face many challenges as pain, due to disease condition or surgical intervention; anorexia, nausea and vomiting, due to chemotherapy; anxiety due to hospitalization; fear about complications; financial problems due to treatment and collapse the family constitution. [7] Treatments focus on controlling the spread of cancer and promoting good quality of life. Fortunately, a cure may be possible in some cases.

Breast cancer is a common problem which affective to individual who is suffering from disease condition as well as their families too. [8] Most of women have experienced physical pain and discomfort on breast and arm following the surgical intervention. [9] Also, they are facing physical experiences as anorexia, vomiting, oral ulcer due to chemotherapy and following mastectomy. [10] Further, a study related to psychological experiences of fourth stage breast cancer patients revealed anxiety, fear of cancer recurrence and living with uncertainty leading to collapse mental status of the affected women. [11]

The annual mortality rate per 100,000 people from breast cancer in Sri Lanka has increased by 112.4% since 1990, an average of 4.9% a year. [12] Also, emphasized that breast Cancer is the commonest cancer among females in Sri Lanka, with an average of 2500 new cases per year which is approximately 27% of all newly diagnosed cancers detected among females. [13] Even though, only few research studies have done to identify experiences of patients with fourth stage breast cancer in Sri Lanka. Moreover, suicidal attempts were

reported in the oncology unit in Teaching Hospital Anuradhapura due to depression and broken family setup of the women with breast cancer. [14] This study is an attempt to move forward on their issues. So, this study will help to enhance the quality of life of the women with fourth stage breast cancer through exploring their experiences and to improve knowledge of health staff, family member and the community regarding patient's thoughts and expectations.

### **Study Purpose**

Purpose of the study is to explore the experience of the young women with early stage breast cancer at oncology unit in Provincial General Hospital Kurunegala, Sri Lanka.

## **METHODOLOGY**

### **Design**

A qualitative phenomenological design was utilized in this study to explore experiences of young women with early stage breast cancer. Qualitative research is primarily an exploratory research. As the experiences are qualitative and difficult to quantify, qualitative approach is used to gain an understanding of underlying reasons, opinions and motivations.

### **Study setting and participants**

This study was taken place at the Oncology unit of Provincial General Hospital Kurunegala. This clinic is conducted three days per week for new and registered patients following oncology treatment. The study population get registered at the clinic and referred for further treatments as Radio therapy, Chemotherapy and other investigations.

The target population was the young women with early stage breast cancer in Kurunegala district, Sri Lanka. Twenty women were in age category 20 – 50 years, who have diagnosed with breast cancer 3 to 6 months prior to conduct the study were purposively selected. Their willingness to discuss experiences of the breast cancer and their physical fitness to be with the

researcher during the interview period was also considered when selecting the sample.

### **Ethical consideration**

Ethical approval was obtained from the Ethics Review Committee of the Provincial General Hospital Kurunegala and the permission for conducting this study was taken from the Director of Provincial General Hospital Kurunegala and from the Consultant Oncologist of Provincial General Hospital Kurunegala. All the participants were clearly informed about the purpose of the study prior to taken place the interviews and informed consent was obtained from each and every study participant while encouraging voluntarily participation. Participants' confidentiality was maintained. Anonymity and confidentiality were assured by securing and rotating information only among the research team. In here study participants were labeled using a specific code to assure anonymity. Participants who wish to withdraw from the survey were permitted. Data were stored for three years under lock and key with restricted access only to the investigators. The computerized data were protected with password and only available to the investigators.

### **Data collection**

Semi structured interviews were conducted to collect the data in the participants' mother. The interview theme list was developed in participants' mother (Sinhala) and translated to English. Semi structured interview guide was utilized to guide the interviews that lasted about 20 to 30 minutes and it helped to cover demographic data, medical and surgical history and all relevant issues such as physical experiences, psychological experiences and socio-economical experiences that required investigating in this study. Finally, should allow the interviewee to share and thoughts or opinions that they feel the need to talk about.

The investigators collected the data since 25<sup>th</sup> of August to 20<sup>th</sup> of October in

Oncology Unit, Provincial General Hospital Kurunegala. Voluntary participation was encouraged to take part in the study. Potential participants were informed about the study including the purpose of the study. Participants were convinced about their right to withdraw from the study at any time without any penalty. Written information sheet of the study was given to participants and they were allowed to ask any question for their clarification. In order to maintain the privacy of data, participants were interviewed in a separate room in oncology unit alone, without family members or relative's participation. Length of the interview was concluded by a combination of participant contribution, time taken to discuss the topic guide. Communication skills like keeping silent, careful listening, making encourage noises and looking interested were maintained by researchers during the interviews. Digital voice recorders were used for data collection to maximize the accuracy of information. Other than the voices of participants their natural body language and nonverbal clues were observed by the researchers during interviews.

### **Data Analysis**

Qualitative data which was collected by digital recorders during the face to face semi-structured interviews were analyzed according to content analysis. In here researchers transcribed interviews into text with several reviews. Then researchers read the text in several times and, clustered, coded according to their common features, and derived sub themes followed with general themes. In order to maintain the validity of the study, each transcription was reviewed by interviewers come to an agreement on the extracted themes. Member checking were done to maintain the trustworthiness of the study. Findings regarding, psychical experiences, psychological experiences and socio-economical experiences of patients with fourth stage breast cancers were explored.

## RESULTS

Based on the collected data, demographic details and the experience on discomforts of patients with early stage of breast cancer were described. In this study the average age of the participants was between 20 to 50 years. Majority of participants were literate. Eleven participants were housewives and others were engaged in occupations. At the movement collecting the data, already eight women were left the job. One woman is lived in an extended family and all others were lived in nuclear families. Further,

eighteen participants were married, and others were not.

Three themes were derived from the findings: severe physical discomfort of the body due to disease condition was emerged under physical experiences of the client, emotional disturbances of the client were emerged under psychological experiences of the client and impaired socio-economic life was emerged under socio-economical experiences of the client. Figure 1 is illustrated the experience of the young women with early stage breast cancer as a model.

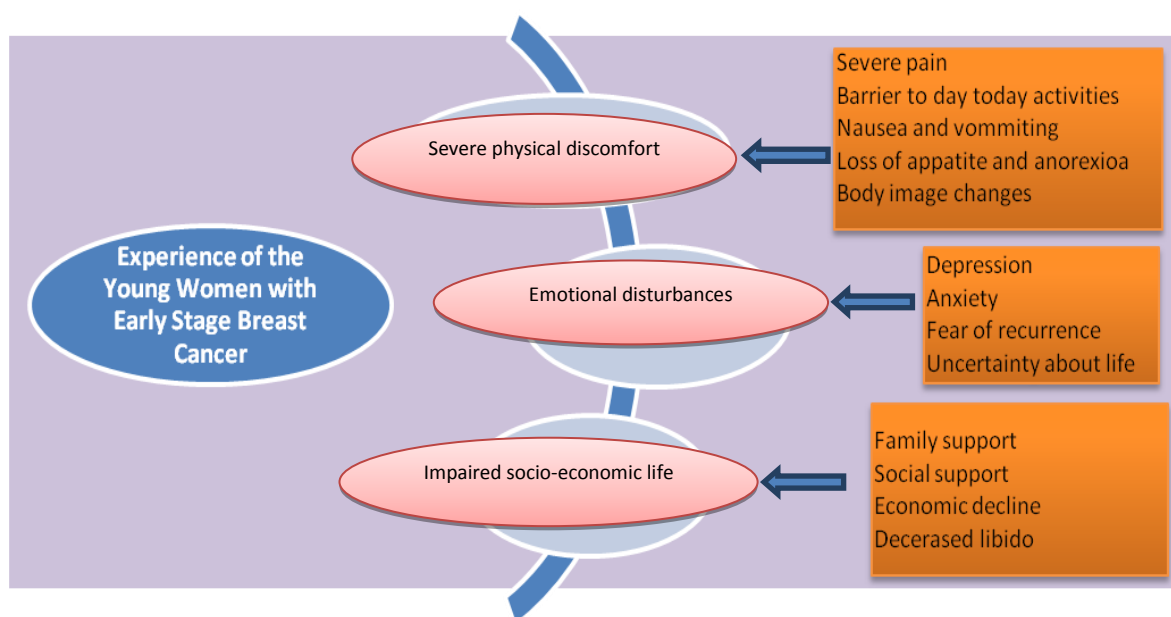


Figure 1. Experience of the Women with Early Stage Breast Cancer

### Severe physical discomfort of the body

Content analysis of the interviews identified severe physical discomfort of the body due to the disease condition as a major theme derived with respect to the physical experiences of the client. Most of the respondents of the study reported, unbearable pain following the surgical intervention. Not only physical discomfort was associated with pain but also accompanying with loss of appetite, nausea, vomiting and anorexia, which can be considered as barriers to conduct day today activities as well as body image changes. All participants had above discomforts in more or less levels.

One of the significant finding was, severe pain on surgical site following the surgical treatments during first twenty- four hours. It can have substantiated by participants' own words:

*"After done the surgery I felt severe pain within first twenty-four hours. Nurses gave me medications for pain, but not settled"* (Client Ms. 3)

With the initiation of chemotherapy, they have developed nausea, vomiting, severe anorexia and hair loss. Usually those are the side effects of chemotherapy. Client Ms. 9 and Ms. 14 described their experiences as:

*“Ane..... I can remember. After getting first dose of medicine, I had severe vomiting. I could not eat anything. My weight loss rapidly when continue treatment. Always I was in severe body ache. I could not do even my daily duties” (Client Ms. 9)*

*“oh.....I lost my hair day by day. I used many kinds of traditional treatment for prevent it. But couldn't control it. Lastly, I lose my all hair within 2 months. Ayoo...I those days I never looked my face in a mirror” (Client Ms. 14)*

After the client had undergone the surgical interventions, they had to adhere to some restrictions like, avoid lifting weight more than half of kilo grams, avoid sleep towards surgical side etc. Women couldn't perform their day today activities and they need assistance of some one. Also, most of the times they were hospitalized to get treatments and to perform investigations. Therefore, they have not enough space to engage with day to day activities by themselves as they are ill. It can be substantiated by participants own words as:

*“Before I leave the ward nurses and doctors told me not to have more than half of a bread by hand on surgical site” (Client Ms. 10)*

### **Emotional disturbances**

Emotional disturbances due to the disease condition is comply with psychological experience of the participants. Depression, fear of recurrence, anxiety, and uncertainty about life were emerged as sub themes under the main theme of emotional disturbances.

Women with early stage breast cancer had so many stresses since they diagnosed with the disease condition and after. The level of emotional disturbances was fluctuating periodically: when did the diagnosis, during the period of surgical intervention, chemotherapy and radiotherapy and when performing the investigations. On the other hand, clients' felt with anxiety about the uncertainty about their lives, fear of recurrence, impact towards the family, economic status and

expected difficulties etc. Emotional disturbances were reflected by the participants as follows:

*“Oh..... when I heard first time this.... I could not think what I will do next. I cried over few moments. How I say this to my family. I felt burning in my body. Finally, I thought suicide is better than live” (Client Ms. 2)*

*“Not only me but also my family members are in terrible disaster, suddenly it hits our heads, like a bomb. It blasts all our dreams. We are very poor people. Recently we put a foundation for own house. I know that hereafter we can't spend on building our own house. Until our death we will have to stay in rented houses” (Client Ms. 11)*

### **Impaired socio-economic life**

According to the findings of the study, family support was caused to build or collapse women's social life. In current study all clients had considerably positive family support in various ways to perform physical activities, to build up mental status. Investigation procedures for the disease condition and its treatments were in high cost. But most of the times, these costs were carried by Sri Lankan government heavily. But some investigations to be done from the private sector due to its emergency. Further, most of the clients were resigned from their jobs as a result of impending disease condition. The family has to bear all expenses on her regards. Therefore, most of the time her husband has to take care of all these things alone. A rapid decline of socio-economic level is more common.

*“I was unable to go for my job regularly. I couldn't also work over eight hours. It was lost. Because it was a temporally job. After that I couldn't manager economical problem of my family” (Client Ms. 17)*

*“After I got ill, I couldn't go to fair for business, When I knew about my illness my husband didn't farm well. Every time he come with me when I go to treatment that cause to increase our outcome and decreased income” (Client Ms. 8)*

The communities of this area had strong interpersonal relationships under cultural

influences. As a result, relatives and neighbors were more helpful during the period of treatment for the victims and many of clients were emphasized the family and social support happily as:

*“When neighbors knew about my illness, they reassured me and encouraged me for treatment” (Client Ms. 12)*

Sexual problems were another cause which associated with corporeal discomfort. Clients and their sexual partner (husbands) avoid voluntarily their sexual activities after got illness due to possible discomforts of the client and negative feeling of the client.

*“My husband loves me a lot. He understood the situation and my feelings. He didn’t motivate me to sexual activities” (Client Ms. 18)*

## **DISCUSSION OF THE STUDY**

The findings of the study revealed that women with early stage breast cancer underwent different types of experiences regarding their physical, psychological and socioeconomic life. In the process of analysis, three major themes were derived from the obtained findings as severe physical discomfort due to disease condition, emotional disturbances and impaired socio-economic life.

### **Severe physical discomfort of the body**

Almost all the respondents in the study population complained about the unbearable pain following the surgical intervention. Because of the severe pain occurred in the surgical site and related muscle, they faced lot of difficulties when move the arm. Similar results were reported in a study done in Korea. [23] They showed that most of women with advanced stage breast cancer experience severe post-surgical pain around arm and shoulder.

After clients treated with chemotherapy and radiotherapy was presented with loss of appetite, severe anorexia, nausea vomiting and hair loss. That caused to change their life pattern individually. This result was compatible with a study done in India. This study

concluded that not only pain but also patients were presented with anorexia, nausea, vomiting, oral ulcer and loss of appetite due to chemotherapy and radiotherapy. [10] In addition, chemotherapy-induced vomiting has been ranked as one of the most distressing side-effects among women and vomiting was one of the most worrisome side-effects because it had drastically influenced their eating appetite. [15]

Actively involved in day today activities were most important to the clients to maintenance of the regularity of life. But immediate after surgery and during chemotherapy clients had barriers to engage in day today activities due to pain and other discomforts. In here they have experienced significant impairment in their daily life. This finding was proved by the studies conducted by in South Africa and Malaysia respectively. [15,16] They identified activity limitations, upper extremity motion restrictions, lymphedema, pain and chemotherapy induced peripheral neuropathy as well-known physical impairments in a study. Further mentioned that, one of the most common problems encountered by them was having no appetite to eat, because everything felt tasteless, and they also feel nauseous. Based on these side-effects of chemotherapy had affected their quality-of-life.

### **Emotional disturbances**

The study participants had to face many stressful situations based on their disease condition. Most of the time they are playing a main role in the family, as a mother, housewife and earner of the family. Once they diagnosed with the disease condition and there after respondents’ mental stability rapidly gone down and the result is emotional dizziness. This finding was compatible with the results of the studies; as clients experience high level of stress associated with fourth stage breast cancer. [17,18,19] Furthermore, contrast to present study found that there were no changes in the level of depression over the period of disease. [15]

In addition to depression, anxiety and fear of recurrence were also common psychological conditions experienced by study participants. These findings collaborate with a study done in Pakistan. [19] This qualitative study found that women with early stage breast cancer recognized that their anxiety and fear had tendency to fluctuate in far with their emotional well-being.

Uncertainty about life was most important thing need to eliminate during treatment stage. The subtheme of uncertainty about life captured in this study were similar to the findings of Banning who identified that women with early stage breast cancer experience uncertainty as well as constant worrying about their future health due to the possibility of cancer recurrence. [19] Changing body image was mostly affects to client to collapse their mental status as they are still young. Findings of the study shown that all participants were worried about changes of the body image due to the diseases condition and following the chemotherapy. It was found that more than half of the patients experienced hair loss after chemotherapy. [15] Study participants were used scarf or wig for hiding their hair loss. Also, they worried about their spouse due to own damaged look. This result was compatible with Ng, Ong, Jegadeesan & Celettial who showed that the changes of the appearance were affected to collapse mental status. [10] Further mentioned that even though their hair will grow again after the completion of chemotherapy, many patients still feel distressed, as they think that it represents a sign of cancer patient on chemotherapy. [15]

### **Impaired socio-economical life**

In this study women were talked about the support of family and community in positive way. Also reported family support was found to be an associated factor for maintain social life of clients. [20] The participants of this study explained how they gradually cope with their disease

condition with social support. This result was compatible with a study done by Sadler-Gerhardt, Reynolds, Britton and Sharon Kruse. [21]

Furthermore, economic decline was a common factor that participants were experiencing as a negative consequence of the disease condition. The underlying reasons were they are acting as earners, expend more money in treatments and investigations and usually women are managing household expenses. Also, these women's husbands were not engaging with their profession actively as they have to look after the diseased wife and children. The ultimate result is declining the economic status of the family. Studies found that all clients got economical declines drastically when they acquire to fourth stage breast cancer. [16,18,20]

Moreover, clients restricted the sexual activities due to physical discomforts and emotional dizziness. Also, husbands of the affected women do not willing to force to the diseased wife to engage in sexual activities as they really worried about wife. Similar findings were reported. [22] Further he emphasized that women undergoing breast cancer felt that their cancer had a negative feeling of their sex life and sexual problems were arisen due to lack of desire.

### **CONCLUSIONS**

Young women with early stage breast cancer are encountered with challenging experiences to their life. Three themes related to experiences of the young women with early stage breast cancer were derived from this study. They are severe physical discomfort due to disease condition, emotional disturbances and impaired socio-economic life. Unbearable pain following the surgical intervention, interrupt day today activities, nausea and vomiting, loss of appetite, and hair loss located under major theme of severe physical discomfort of the body. Further, depression, fear of recurrence, anxiety and uncertainty about life were identified under emotional disturbances. Furthermore,

changing of body image was also a crucial factor in respondents' life. Majority of participants tried to hide the changes of appearance using different strategies to hide their collapsed mental status. Moreover, majority of the participants in this study have received family support and social supports. They were able to continue their treatments regularly with supportiveness of those categories while economic decline, decreased libido and loss of sexual activities were identified as negative socio-economic experiences.

### **Recommendations**

Women with early stage breast cancer experienced various difficulties in physically, psychologically and socio-economically which directly affect to the quality of the life from initiate to become complete recovery. As they are still in early stage of breast cancer, need to get immediate actions to prevent metastasis and prognosis to other complicated stages. So, it is recommended to conduct awareness programs for the affected women, family members and social groups. The results of this qualitative research help nurses to be able to help these women by being aware of their feeling and experiences. In this regard, one of the nurses' tasks is to help women find mechanisms to cope with breast cancer such as providing information, helping them to find other women with similar experiences to share, as well as informing women's spouses regarding the patients' emotional and physical needs. This can be done in educational or consultation sessions and can help spouses to understand their wife's problems better, and consequently this can help the woman. Moreover, this study recommended that the government need to arrange appropriate methods and procedures to secure their economic, social statuses while protecting their life standards significantly.

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