



## A quantitative study of experienced young women by Early Stage Breast Cancer

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### ABSTRACT

The cells in the breast begin to grow out of control is called breast cancer. This is classified into stage zero to stage four according to the amount of severity and nature of spread. During the early stage, diagnosis of cancer and the beginning of treatments are directly affected to quality of life of the young women. Most of the women have unpleasant physical, psychological, and socio-cultural experience due to impairments and functional limitation secondary to breast cancer. 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.



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### INTRODUCTION

Breast cancer is the most prevailing cancer in women as well as the second most common cancer reported overall in the world (Bray *et al.*, 2018). There were over 2 million new cases reported in 2018 (World Health Organization, 2018). 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 non-melanoma 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 (Mandal, 2017). Cases of invasive breast cancer and survival rates range from 40% in low-income countries to more than 80% in other countries (National Breast Cancer Foundation, 2018). Thus, it will become a major health burden both in developed and developing countries.

Breast cancer has been known to mankind since ancient time (Kemal et al., 2012). It is divided into stage zero to stage four according to the amount of the spread and the nature of the spread (Grip-srud et al., 2016). Among them, fourth stage breast cancer is extended beyond the immediate region of the tumour 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 (Hack et al., 1999). 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 (Ng et al., 2017). Most of women have experienced physical pain and discomfort on breast and arm following the surgical intervention (Kyriacou et al., 2017). Also, they are facing physical experiences as anorexia, vomiting, oral ulcer due to chemotherapy and following mastectomy (Global Burden of Disease Study, 2015). 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 (Nies et al., 2018).

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 (Radina et al., 2007). 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 (Ashing-Giwa et al., 2013). Even though, only a 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 (Clayton et al., 2008). 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 the oncology unit in Provincial General Hospital Kurunegala, Sri Lanka.

## MATERIALS AND METHODS

### Design

A qualitative phenomenological design was utilized in this study to explore the experiences of young women with early-stage breast cancer. Qualitative research is primarily 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 the 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 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 taking 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 labelled 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 a 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 the 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, it 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 the 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 non-verbal clues were observed by the researchers during interviews.

### Data Analysis

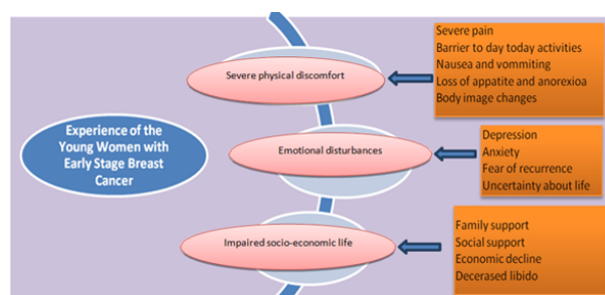
Qualitative data which was collected by digital recorders during face to face semi-structured interviews were analyzed according to content analysis.

In here, researchers transcribed interviews into text with several reviews. Then researchers read the text 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 was 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 AND DISCUSSION

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 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 the surgical site following the surgical treatments during the 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 the first dose of medicine, I had severe vomiting. I could not eat anything. My weight loss rapidly when I 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 two 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 kilograms, avoid sleep towards surgical side etc. Women couldn't perform their day-today activities and they need the assistance of someone. 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 are complied with the 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 con-

dition 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 about what I will do next. I cried over a 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 a 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 our 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 the 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 manage economical problem of my family" (Client Ms.17)

"After I got ill, I couldn't go to the 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 causes 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 neighbours 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 neighbours 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)

The findings of the study revealed that women with early-stage breast cancer underwent different types of experiences regarding their physical, psychological and socio-economic 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 a lot of difficulties when moving the arm. Similar results were reported in a study done in Korea. They showed that most of the women with advanced-stage breast cancer experience severe post-surgical pain around the 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 ([Global Burden of Disease Study, 2015](#)). 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.

Actively involved in day-to-day activities were most important to the clients to the maintenance of the regularity of life. But immediate after surgery and during chemotherapy, clients had barriers to engage in day-to-day 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 ([Banning, 2014](#); [Cui et al.,](#)

[2014](#)). 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 thereafter, 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 a high level of stress associated with fourth stage breast cancer ([Sadler-Gerhardt et al., 2010](#); [Boyle et al., 2017](#); [Kim et al., 2011](#)). Furthermore, a contrast to the present study found that there were no changes in the level of depression over the period of the disease.

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.

([Kim et al., 2011](#)) 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 the most important thing need to eliminate during the treatment stage. The subtheme of uncertainty about life captured in this study was 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 ([Kim et al., 2011](#)). Changing body image was mostly affects the client to collapse their mental status as they are still young. Findings of the study showed that all participants were worried about changes of the body image due to the disease's condition and following the chemotherapy. It was found that more than half of the patients experienced hair loss after chemotherapy ([Banning, 2014](#)). Study participants were used a scarf or wig for hiding their hair loss. Also, they worried about their spouse due to their 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 ([Global Burden of Disease Study, 2015](#)). Fur-

ther 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 (Banning, 2014).

### Impaired socio-economical life

In this study, women were talked about the support of family and community in a positive way. Also reported family support was found to be an associated factor for maintain the social life of clients. 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.

Furthermore, the 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 deceased wife and children. The ultimate result is declining the economic status of the family. Studies found that all clients got economic declines drastically when they acquire to fourth stage breast cancer (Cui et al., 2014; Boyle et al., 2017).

Moreover, clients restricted sexual activities due to physical discomforts and emotional dizziness. Also, husbands of the affected women do not willing to force the diseased wife to engage in sexual activities as they really worried about the wife. Similar findings were reported. 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 the experiences of 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 a major theme of the 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, the majority of the participants in this study have received family support and social supports. They were able to continue their treatments regularly with the supportiveness of those categories while economic decline, decreased libido and loss of sexual activities were identified as negative socio-economic experiences.

### Conflict of Interest

The authors declare that they have no conflict of interest for this study.

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