BREAST CANCER SURVIVORSHIP EXPERIENCES: A RETROSPECTIVE COHORT STUDY BASED ON CANCER REGISTRY IN NORTHERN KERALA

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A THESIS SUBMITTED BY

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IN PARTIAL FULFILMENT OF THE REQUIREMENTS

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DECLARATION BY THE STUDENT

I, **Neethu A. P.** hereby certify that I had personally carried out the work depicted in the thesis titled, **"Breast cancer survivourship experiences: A retrospective cohort study based on cancer registry in Northern Kerala"**.

No part of this thesis has been submitted for the award of any other degree or diploma prior to this date.

Signature

Date 12. 6. 2023

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The thesis entitled, **"Breast cancer survivourship experiences: A retrospective cohort study based on cancer registry in Northern Kerala"** was carried out under my direct supervision. No part of the thesis was submitted for the award of any degree or diploma prior to this date.

Clearance was obtained from the Institutional Ethics Committee for carrying out the study.

K. Srinivasan

Signature

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APPROVAL OF THE THESIS

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Helped me grow, and then,
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AAR	Age-Adjusted Rates
ASCO	American Society for Clinical Oncology
ACS SCS	The American Cancer Society Studies of Cancer Survivors
BCS	Breast Conservation Surgery
BHGI	Breast Health Global Initiative
BSE	Breast Self-Examination
CCRC	Cochin Cancer Research Centre
DALYS	Disability Adjusted Life Years
ER PR status	Estrogen Receptor Progesterone Receptor Status
FIOH	Finnish Institute of Occupational Health
FISH	Fluorescent *in situ* hybridization test
GAD	Generalised Anxiety Disorder
HBCR	Hospital Based Cancer Registry
HCW	Health Care Worker
HER 2	Human Epidermal Growth Factor Receptor 2
IARC	International Agency for Research on Cancer
ICD 10	International Classification of Diseases version 10
ICMR	Indian Council of Medical Research
IEC	Institutional Ethics Committee
IHC	Immunohistochemistry
IOM	Institute of Medicine
IQR	Inter quartile range
MCC	Malabar Cancer Centre
MRM	Modified Radical Mastectomy
NCI	The National Cancer Institute
NCCN	National Comprehensive Cancer Network
NCCS	The National Coalition for Cancer Survivorship
NCRP	National Cancer Registry Program
OPD	Out Patient Department

OR	Odds Ratio
PBCR	Population Based Cancer Registries
PHQ-9	Patient Health Questionnaire-9
QOL	Quality of life
RCC	Regional Cancer Centre
RCT	Randomised Controlled Trial
RTW	Return to Work
SEER	Surveillance, Epidemiology, and End Results
TCC	Tertiary Cancer Centre
UHID	Unique Hospital Identification Number
UK	United Kingdom
USA	United States of America
WAI	Work Ability Index
WHO	World Health Organisation

SYNOPSIS

Globally, incidence and mortality related to cancer are increasing yearly, as evidenced by the GLOBOCAN reports published by the International Agency for Research on Cancer (IARC). Among all cancers, breast cancer in women is the most commonly diagnosed cancer as per the latest GLOBOCAN reports of 2020. This increase is also seen in developing countries, attributed to the adoption of the western lifestyle by the population. The reports from cancer registries from different parts of India also show an increase in the incidence of breast cancer every year. Advances in early detection, diagnosis, and treatment including in low- and middle-income countries contributed to better survival and an increase in the number of people living with breast cancer now referred to as a 'cancer survivor'. Another term in use is "survivorship". According to the National Cancer Institute, "Cancer survivorship" includes the entire cancer continuum, from the initial diagnosis through the balance of a cancer patient's life including the caregiver. This definition includes the physical, social, mental, and financial effects of cancer faced by the patient and caregiver beyond the diagnosis and completion of treatment. It also covers issues related to follow-up after completion of treatment, the possibility of recurrence of cancer, second cancers, and quality of life. According to the American Cancer Society survivorship has three distinct levels or phases: 1. Acute level of survivorship that begins with diagnosis and current/active treatment. 2. Extended level that begins when treatment has ended, but treatment effects remain, and 3. Permanent survivorship is when the chance of cancer recurrence begins to decrease, but long-term effects may remain indefinitely.

Breast cancer treatment in itself has many side effects depending on the type, duration, and dose of treatment and the patient's age at diagnosis. Some side effects persist even after the completion of treatment or become apparent months or years after treatment completion. These include long-term health effects like pain, fatigue, lymphoedema, and those due to hormone treatment like menstrual changes, hot flashes, and mood variations. Literature shows that breast cancer patients suffer from increased anxiety and depression during treatment and some of them also continue to have these symptoms even five years after treatment.

As evidenced by literature, clinicians are more concerned with dealing with the side effects of the treatment, and examining for signs and symptoms of a relapse; but a cancer survivor may be concerned about the day-to-day discomfort, which includes hot flashes from hormonal treatment, weight gain, numbness of the arms and cognitive issues. Many also suffer from loss of job, and social stigma, while others try hard to cope and move forward in life. Four million women are living with breast cancer in the United States as of 2022, with similar numbers in the rest of the world. 30 million three-year, and 44 million five-year survivors of cancer live globally, with more than half of them in low and middle-income countries. In India, 459 thousand women are living with breast cancer according to five-year prevalence statistics from GLOBOCAN 2020. Understanding and addressing the needs of breast cancer survivors is important for improving the quality of life of every survivor.

Studying survivorship has many challenges. The major task is identifying the study participants. Most of the studies are conducted from hospital medical records, hospital outpatient department records, or cancer registries in Western countries. Cancer registry is a method of cancer surveillance in many countries and is used in the analysis of temporal trends, future predictions, and survival of various cancers. In India, there are two types of registries - the Hospital-Based Cancer Registry (HBCR) which contains the data of all cancer patients who were registered in a hospital in a particular year, and the Population-Based Cancer Registry (PBCR) which helps in understanding the prevalence of particular cancers in the community. The study setting of the present study was a Tertiary Cancer Centre (TCC) with a well-developed Cancer Registry Department, having an HBCR where all patients registered in a particular year from January to December were included. Since studies on long-term survivors of more than five years are scarce, we decided to conduct the study on breast cancer patients included in the HBCR of the year 2016.

The study design of the present study is that of a retrospective cohort. The present study starts from a retrospective collection of data on breast cancer survivors, registered in the year 2016 in the TCC(n=534). The cohort of survivors was followed up in 2022 (n=209) and a survey was done to understand their long-term health effects, work ability, anxiety, and depression. It was also of interest to find out whether experiencing the disease has improved awareness about the symptoms and risk factors of breast cancer among survivors and to understand the barriers they faced during the help-seeking process. Hence, these were included as sub-objectives. In-depth, interviews were conducted among selected survivors to have a deeper understanding of their survivorship experience(n=20). Taking the above facts into consideration, the following objectives were formulated for the present study:

Primary objectives:

1. To describe the profile of breast cancer patients based on the Hospital Based Cancer Registry (HBCR) of the year 2016 from a Tertiary Cancer Centre.

2. To study the post-treatment effects of breast cancer patients in the HBCR of 2016 from a TCC after six years of follow-up in 2022

3. To explore their survivorship experiences

4. To study policy associated with the survivorship of breast cancer in Kerala.

Secondary objectives:

1. To study awareness level regarding breast cancer among survivors
2. To study the help-seeking behavior among breast cancer patients in HBCR of 2016 from a Tertiary Cancer Centre.

Methods: The study design used is a retrospective cohort. In this study, data on breast cancer survivors are retrospectively collected from the patient records retrieved by using the unique patient identification number that is available in the medical records. These patients had undergone treatment in 2016 and were followed up in 2022. Their survivorship was studied based on different variables like their long-term health effects of treatment, work ability, levels of anxiety, and depression.

The study was conducted in three phases; The first phase was the retrospective collection of data from the patient records. Data based on the HBCR core form of all the breast cancer patients (n=534) registered in 2016 and included in the HBCR was collected. The second phase was the follow-up survey conducted in 2022. As per criteria all breast cancer patients who were under follow-up and were traceable in 2022 were included in the follow-up survey. Those who did not consent to participate, those who were not able to comprehend either because of their old age or mental conditions, those who had a history of anxiety or depression, and/or were under treatment for the above were excluded. The sample size for the follow-up survey was 209. In-depth interviews were conducted among disease-free survivors(n=15) and survivors having recurrence or residual disease(n=10). The third phase of the study included a review of documents related to cancer control, with special reference to breast cancer and breast cancer survivorship in Kerala.

The analysis of registry data of the first phase describes sociodemographic data, stages, and treatment-associated data of all the breast cancer patients in HBCR of the year 2016. Bivariate associations of stages of disease and factors associated with treatment completion were performed for 437 women who were diagnosed in 2016. It also describes the association between sociodemographic and other factors with early-stage presentation and treatment status. The mean age of the survivors was 53.8 years (95% CI 52.77 54.83). It was found that the early stage of presentation was associated with a higher level of education which was also found to be statistically significant. Also, those with early stage of disease at presentation were found to have completed their treatment. Other sociodemographic factors were not found to be associated.

From 2016 to 2022 the size of the cohort had also undergone changes. The cohort of study participants included not only those who were diagnosed in 2016 (n=437) and registered in the TCC but also those who were diagnosed between 1991 and 2015(n=97) but registered for the first time in the TCC during 2016. Considering the lost to follow-up and those who were deceased, the number of survivors was reduced to 274 in 2020. After excluding those who did not consent to participate, were not able to comprehend either because of their old age or mental status and had a history of anxiety or depression, or were under treatment for the same, the participants finally included in the follow-up survey in 2022 were 209.

The follow-up survey conducted in 2022 studied 209 survivors. The basic factors of the survivors were studied to find the association with work ability, anxiety, and depression. Awareness regarding breast cancer and the help-seeking behaviour of survivors was also studied. The tool administered also included factors such as long-term health effects of treatment, and comorbidity status, in addition to sociodemographic factors. Data was collected based on the Work Ability Index (WAI) for work ability, PHQ 9 scale for measuring depression, and GAD 7 scale for measuring anxiety. Additional data regarding awareness about breast cancer and barriers to help-seeking was also acquired. Data was entered into appropriate software, cleaned, and analyzed.

It was found that among long-term effects, those related to treatment-related menopause, including hot flashes and mood changes were found in a maximum number of survivors. Others include fatigue, pain, lymphoedema, numbness of arms, cognition issues, and an increase in weight. When the work ability of the survivors was analysed using WAI, it was found that more than three-fourths of women had good and above work ability. Bivariate analysis showed that work ability was associated with marital status, co-morbidities, age, job, and disease-related factors like pain, fatigue, present disease status, anxiety, and depression. Multiple logistic regression on work ability and predictive factors demonstrated that being married, being disease free, and having a job were associated with good to excellent work ability while having depression, fatigue, and pain were associated with poor work ability. One-fifth of the women had varying anxiety levels from mild to severe. Anxiety was associated with marital status, fatigue, mood changes, numbness and weakness of upper limbs, poor work ability, present disease status, and depression. The prevalence of depression was less than the prevalence of anxiety among survivors and was associated with fatigue, mood changes, work ability, and present disease status. The multiple logistic regression predicted that anxiety and poor work ability increase depression among survivors. The assessment of awareness levels regarding risk factors and symptoms of breast cancer among survivors, revealed similar or lesser levels of awareness when compared to the general population in some areas. This means that going through the whole cancer journey did not have much effect on their awareness level. The general population often considers ‘cancer survivors’ as ambassadors, and they can be used in disseminating the message that breast cancer is a curable disease. Hence, we feel that it is important to improve their level of awareness for the correct messages to be disseminated.

In-depth interviews conducted among the survivors also opened up many issues faced by the women. Various themes like body image concerns, post-treatment sex life, fear of recurrence, social exclusion, socioeconomic support, and service needs of the survivors evolved, which gave new insights into the meaning of survivorship as experienced by these women.

Documents related to policy regarding breast cancer control and survivorship were analyzed. Four policy documents were included for review. They are (1) Ten-Year Action Plan for Cancer Control in Kerala (1988), 2. Draft Health Policy (2013), 3. Kerala Cancer Control Strategy (2018), and 4. Health Policy (2019). The analysis was based on mentions about cancer control, cancer registration, follow-up, and survivorship plans. The findings reveal that there was no policy for survivorship care or plans for long-term follow-up of breast cancer patients.

This study was an attempt to understand the various long-term physical effects as well as the psychosocial issues faced by breast cancer survivors after six years of completion of their treatment. In our study, we discussed breast cancer survivorship in terms of work ability, anxiety, and depression among survivors. The findings of the study suggested that the post-treatment physical and psychosocial side effects have affected their ability to perform their daily activities in the form of reduced work ability and varying levels of anxiety and depression. Understanding the issues faced by the survivors and intervening at the right time will definitely improve their quality of life.

The Organisation of the thesis

The introductory chapter discusses the burden of cancer, followed by the definition of the cancer survivor, the importance of studying them, and the importance of the cancer registry. The literature review section describes the currently available literature on survivorship among all cancers specifically on breast cancer. There are gaps in the literature such as scarcity in studies related to long-term survivors, scarcity of studies about survivors utilising registry data, and the dearth of such studies in Kerala, especially from the Northern area. This has become the basis for the present study focusing on the survivorship experiences of breast cancer patients. The third chapter is devoted to research methodology including study setting, study population, tools and measurements, analysis, and ethical considerations. Chapter four has three major sections including the results describing the profile of HBCR 2016 patients with breast cancer(n=534), analysis of the stages of cancer, analysis of the follow-up survey (n=209) conducted among those who were traceable after six years in 2022 and who consented. The chapter further described the survivors and the association of various factors with work ability, anxiety, and depression. The factors that were predictors were sociodemographic factors and the late effects of treatment. The variables that were found in the literature and statistically significant in the chi-square/ Fischer exact test were included in multivariate analysis. In addition, the chapter also describes awareness of signs and risk factors of breast cancer among survivors and the barriers to their help-seeking. The chapter's third section is devoted to in-depth interviews of 25 survivors with necessary narratives. The fourth section is devoted to document analysis of four policy documents on cancer control in Kerala. Chapter four discusses the major results of the registry data, follow-up survey study, and policy. Following this, the researcher synthesized all the above findings in the realm of survivorship. The last chapter concludes the findings of the study and suggests a set of recommendations.

INTRODUCTION

Chapter 1

Introduction

"It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can".

Dr. Fitzhugh Mullan, from his essay Seasons of Survival: Reflections of a Physician with Cancer, New England Journal of Medicine, July 1985.

1.1: Cancer Survivor

'Survivor' is a person who remains alive after an event, in which others have died. The word 'cancer survivor' may mean different to different persons. It is a general term describing a person who had a diagnosis of cancer (*Cancer.Net*, 2010) or a clinical term for persons who are cancer-free for at least five years after treatment (Bell and Ristovski-Slijepcevic, 2013).

Due to the advances in treatment, the number of persons living for years after a cancer diagnosis is also on the rise, with an estimated eighteen million cancer survivors in 2022 in the United States, as per triennial reports published by the American Cancer Society, and National Cancer Institute(Miller et al., 2022). The term 'cancer survivor' was first used by Fitzhugh Mullan, who was a physician and a cancer survivor (Bell and Ristovski-Slijepcevic, 2013). Many other definitions were also used which primarily differ in the description of the population covered by the term; some definitions include only the individual having cancer, while others include caregivers and near and dear ones. Thus, there is a lack of consensus regarding whom to call a 'survivor' as per literature(Knaul et al., 2020). However, the most accepted definition is the one given by The National Coalition for Cancer Survivorship (NCCS), a cancer advocacy group founded in 1986, which was later accepted by National Cancer Institute (NCI). As per definition, an individual is considered a "cancer survivor" from the time he/she is diagnosed with cancer to the remainder of his/her life. Near and dear ones of a cancer patient are also equally jolted by the diagnosis, hence they were also included in the definition (Denlinger et al., 2014). Accordingly, there are many types of survivors – those free of cancer and those living with cancer (*National Cancer Institute, Division of Cancer Control and Population Sciences, Office of Cancer Survivorship*, 2022). In 1985, Dr. Mullan published the first article on his experiences as a cancer survivor, where he stated that regardless of the outcome of the disease (whether you are cured or not), cancer patients share common experiences which are specific to them, that are different from the general population (Bell and Ristovski-Slijepcevic, 2013). Dr Mullan's article was an eyeopener, and was taken up by those working in area of cancer and those affected by cancer having similar experiences. It gave the message that completing cancer treatment, and being declared cancer free was not the end, the reality was different for the survivor (Bell and Ristovski-Slijepcevic, 2013).

1.2: Cancer survivorship

The term "Cancer survivorship" is defined as 'the experience of living with, through, and beyond a diagnosis of cancer' by NCCS, a cancer advocacy group founded in 1986 by Mullan, along with representatives from other organisations (Institute of Medicine and National research council, 2006). A significant role was played by the report *From Cancer Patient to Cancer Survivor: Lost in Transition*, published in 2006 by a committee constituted by the Institute of Medicine (IOM), for turning the attention of the world towards survivorship. Dr Mullan stated in his article, that cancer survivorship can be listed as the three different seasons of the year as follows; 1) acute phase which starts from diagnosis to the completion of initial treatment and is replete with treatment related issues 2) Extended phase which begins with the completion of treatment, and mainly deals with the aftermaths of treatment 3) Permanent phase, when the chances of cancer recurrence decreases, but long term effects of treatment remain (Aziz, 2007a). Long-term cancer survivors are defined as those individuals who have completed five years or more after their cancer diagnosis and can be considered as equivalent to the concept of ‘permanent phase’ described by Mullan (Aziz, 2007a).

1.3: Breast cancer survivorship

‘Breast cancer survivorship’ refers to the period between the initial cancer treatment and end of life, in a woman’s cancer journey (Bell and Ristovski-Slijepcevic, 2013). The five year relative survival rates of breast cancer have increased from 75% in 1971 to 91% in 2018 in the United States(US), as per report of American Cancer Society, due to advancements in early diagnosis and treatment (Miller et al., 2022; Siegel et al., 2023). A review of Indian studies on breast cancer survival shows a five year overall survival of 42% to 66% (Sathwara, Bobdey, et al., 2017), with rising trends from 1988 to 2000 as per reports from rural cancer registry of Barshi (Jayant et al., 2011). A cancer hospital in Kerala reported five and ten-year breast cancer overall survival of 79% and 66% respectively(Viral et al., 2021). Breast cancer is one of the three most prevalent cancers in US, with an estimated four million women living with a history of breast cancer in 2022 (Miller et al., 2022). With the increasing number of women living with breast cancer, survivorship should focus on the health and wellbeing of the survivor (*National Cancer Institute*, 2011).

1.4: Breast cancer

Breast cancer, which originates in the breast tissue can arise either in the lining cells of the ducts (85%) or lobules(15%) in the glandular tissue of the breast(WHO, 2021). Cancer can occur either in the central portion of the breast, upper inner quadrant, lower inner quadrant, upper outer quadrant, lower outer quadrant, axillary tail of breast, or can be overlapping.

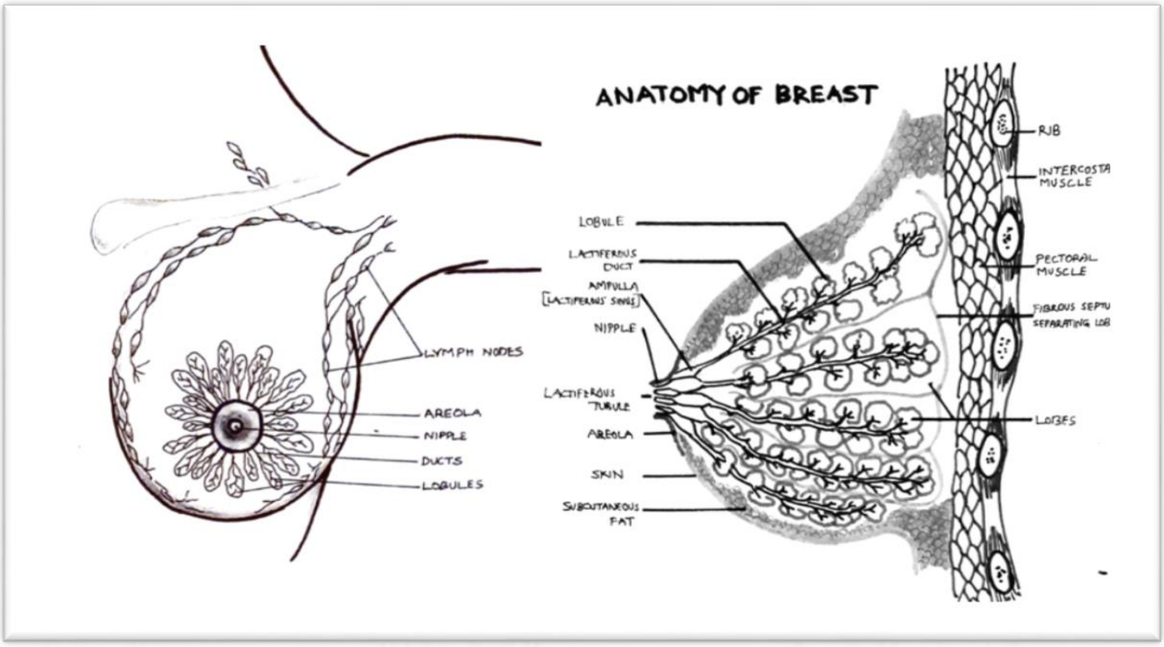
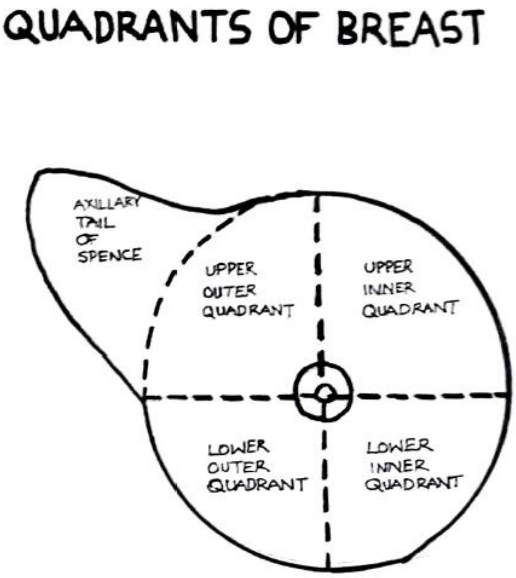


Figure 1.1: Anatomy of the breast



The ICD 10 (International classification of diseases version 10) coding for breast cancer is C50 with the following codes for sites; nipple and areola(C50.0), the central portion of the breast(C50.1), upper inner quadrant(C50.2), lower inner quadrant(C50.3), upper outer quadrant(C50.4), lower outer quadrant(, C50.5), axillary tail of breast(C50.6), or overlapping(C50.8) and breast unspecified(C50.9) respectively (WHO, 2016).

Figure 1.2: The quadrants of the breast

Early diagnosis is the key to cure of breast cancer which decides between life and death for the patient(Becker, 2015). Microscopic confirmation is mandatory for diagnosis with histology and grading (Akram et al., 2017). Major histological type is the invasive ductal carcinoma followed by lobular carcinoma, papillary carcinoma, medullary carcinoma, mucinous carcinoma, phyllodes tumour, sarcoma, and Paget's disease (ICMR-NCDIR, 2021).

1.4.1: Breast cancer: The global scenario

Out of all cancers globally, female breast cancer contributes to 11.7% with 2.3 million new cases diagnosed in 2020 (Sung et al., 2021). In 159 countries of the world, breast cancer is the leading among all cancers. Although overall incidence rates are more in transitioned countries(59.5 per one lakh), the rates are increasing in transitioning countries(29.7 per one lakh) like South America, Africa and Asia.(Sung et al., 2021), mainly due to the demographic transition in those countries (Becker, 2015). It is the fifth leading cause of cancer mortality, and is responsible for one in six cancer deaths in the world (Sung et al., 2021). The mortality rates are 17% higher in transitioning countries, with high fatality rates in Western Africa and the Caribbean (Sung et al., 2021). Age of disease presentation is highest in 40 to 50 years in Asian countries, and 60 to 70 years in the western countries(Leong et al., 2010). Racial differences in distribution of breast cancer is noted with 41% more mortality among black women, though incidence is higher among whites (Siegel et al., 2023). Brazil, Russia, India, China, and South Africa (BRICS countries), where 40% of the world's population live, are challenged by increasing trends in incidence and mortality in breast cancer (Basu et al., 2020). About 0.5%-1% of breast cancer occur in men. (WHO, 2021).

1.4.2: Breast cancer: The Indian scenario

In India, breast cancer is the most common cancer among both sexes and constitutes 26.3% of woman cancers with a cumulative risk of 2.81 (IARC, 2020). An increase by 39.1% in age-standardised incidence rate of breast cancer, has been reported in every state of India during the last 26 years starting from 1990 (Dhillon et al., 2018).

From 1985 to 2014 a significant increase in breast cancer incidence has been observed in all PBCR’s (1.2% in Delhi to 2.7% in Bangalore) (Sathishkumar et al., 2021). Study in 2013 estimates that the projected incidence rates of breast cancer for 2026 is about 0.23 million (D’Souza et al., 2013). Hospital Based Cancer Registry (HBCR) data from South Indian states from 2007 to 2014, shows an increase in incidence of woman cancers generally, with breast and cervical cancer being the most common (Rajan et al., 2021).. South Asian countries including India also show a rising trend in breast cancer mortality and this trend is expected to continue to the next decade as well (Mubarik et al., 2022). This is because, more than half of breast cancer patients here present in late stages(Fan et al., 2015). Breast cancer was also responsible for the second highest DALYS (Disability Adjusted Life Years) in India (8.2%) in 2016 (Dhillon et al., 2018).

1.4.3: Breast cancer: The Kerala scenario

Data from Kerala are available from Population Based Cancer Registries (PBCR) and HBCR of the three Tertiary Cancer Centres (TCC), some medical colleges and selected private hospitals that provide cancer treatment. Generally, Kerala has lower woman cancer rates in both rural and urban areas compared to urban areas in other parts of the country. However, significant increase in the rates of breast cancer, close to that of urban registries in metropolitan cities is noted in urban Trivandrum (Jayalekshmi et al., 2006). Study based on PBCR in Karunagappally and Trivandrum show that the age adjusted incidence rates (AAR) of cancer in women in Kerala is only 35% of that in Aizawl, and also shows minimal urban rural difference (Jayalekshmi et al., 2006). Thiruvananthapuram district ranked sixth among all PBCR’s in India in breast cancer incidence, with an AAR of 35.6 per one lakh population (ICMR-NCDIR, 2020b). Data from Northern Kerala is based on the HBCR and PBCR from Malabar Cancer Centre, Thalassery. As per latest published HBCR data in 2020, breast cancer is the leading among all cancers irrespective of sex (797 cases) and constitutes 30.7% of women cancers in Northern Kerala, peak age group being 50 to 54 years (Malabar Cancer Centre, 2023). In comparison with the previous year HBCR reports an increase of 1.6% is observed in that region (Malabar Cancer Centre, 2022). HBCR report of the year 2015 from Regional Cancer Centre, Thiruvananthapuram in Southern Kerala, reported 2047 cases which constituted 28.1% of female cancers (Regional Cancer Centre, TVM, 2020). PBCR of Northern Kerala also shows an age adjusted rate (AAR) of 41.27 and 24.4 per one lakh population in Kannur and Mahe district respectively (*MPBCR Annual Report 2015*, 2020)

1.4.4: Risk factors of breast cancer

Breast cancer incidence is rising significantly over the years due to standards of living, behavioural pattern, and social development indicators of women in India (Maurya and Brahmachari, 2023). Causes of breast cancer are multifactorial. The risk factors are described as modifiable and nonmodifiable factors. The non-modifiable risk factors include being female, older age (80% aged above 50 years), family history (risk increases with number of first-degree relatives with cancer), genetic mutations (mutations in BRCA 1 and BRCA 2 genes), early menarche, late menopause, density of breast tissue, proliferative breast disease, and previous history of breast cancer. Modifiable risk factors include parity, hormone replacement therapy, physical inactivity, obesity, alcohol intake, smoking, and use of oral contraceptives (Łukasiewicz et al., 2021). About half of the woman who develop the disease have no identifiable risk factors except being a female and age above 40 years (WHO, 2021). Prolonged breast feeding and physical activity were found to be protective, while rural residency, low parity, waist hip ratio more than 0.95 (Malvia et al., 2017), increased age at marriage and older age at first child birth (Jayalekshmi et al., 2009) were associated with increased risk in Indian studies. Diet that are high in saturated fat, processed and red meat are risk factors for breast cancer, while high intake of vegetables, fruits, legumes and whole grains lowers the risk (Dandamudi et al., 2018).

1.4.5: Signs and symptoms of breast cancer

Breast cancer most commonly presents as a painless lump(83%) or thickening in the breast (Koo et al., 2017). Other symptoms include alterations in the size, shape, or appearance of the breast, dimpling, redness, pitting or other alterations in the skin, change in appearance of the nipple or skin changes around the nipple(areola), and abnormal nipple discharge. As disease progresses, it can spread to other parts of the body such as lymph nodes or even other organs of the body and cause related symptoms such as fatigue, breathlessness, and back pain (Koo et al., 2017; WHO, 2021). Advanced cancers can even erode through the skin and cause ulcerations (WHO, 2021).

Initially the cancerous growth is confined to ducts or lobes with minimum risk of metastasis or spread. As time advances, these in situ (stage 0) cancers may invade the surrounding breast tissue (invasive breast cancer) spread to the surrounding lymph nodes (regional metastasis) or to distant organs in the body like liver, lung, bone, and brain (distant metastasis). The distant spread accounts for the mortality in breast cancer (WHO, 2021).

1.4.6: Treatment of breast cancer

Treatment strategy follow a curative intent, and decision is better to be taken in a multidisciplinary setting, taking molecular subtype and locoregional tumour load into account (Harbeck and Gnant, 2017). Breast cancer treatment can be highly curative when disease is diagnosed in early stages (WHO, 2021). The multimodality treatment includes surgery, chemotherapy, radiotherapy, hormonal therapy and targeted therapy. Surgery involves breast conservation surgery (BCS) with preservation of breast tissue after removal of the diseased part and mastectomy (MRM) which is the complete removal of the breast. The choice depends on tumour size, feasibility of surgery, clinical phenotype and patients' willingness to preserve the breast. Chemotherapy is the systemic treatment and can be 'neoadjuvant' (before surgery) or 'adjuvant' (after surgery). Radiation therapy is the local treatment which is given after surgery to ensure that cancer cells are destroyed and to prevent recurrence. Endocrinal therapy aims to lower the estrogen levels or to prevent breast cancer cells to be stimulated by estrogen. Biological therapy is quite common in HER2-positive (Human Epidermal Growth Factor Receptor 2) breast cancer patients; major drug used is trastuzumab. Undergoing complete treatment is important for cure (Łukasiewicz et al., 2021; WHO, 2021).

1.4.7: The post-treatment effects in breast cancer

With the advancements in treatment, 80%−85% of breast cancer patients will be cured, especially when disease is diagnosed in early stages(WHO, 2021). The five-year survival of breast cancer largely depends on the stage of presentation; stage I (95%), stage II (92%), stage III (70%) and stage IV (20%). Due to young age and advanced stage at presentation, delayed initiation of treatment, and inadequate/partial treatment many may succumb to the disease(Mehrotra and Yadav, 2022). Many are also lost to follow up from treatment centres with 31.5% and 44.5% lost to follow up at 6 and 12 months in an Indian study (Doval et al., 2020), highest numbers in the first year (Swaminathan et al., 2008). The breast cancer survivors who are cured, are at risk of complications of their previous treatment, long-term relapse (local or systemic) or of being diagnosed with second malignancy elsewhere or in contralateral breast (Becker, 2015).

As stated, the treatment of breast cancer is not without side effects. Long-term effects refer to those side effects or complications of treatment which begin during treatment and continue even after the treatment is completed. On the other hand, late effects refer to those manifestations, which may not present immediately after treatment completion, but may surface after few years. (Aziz, 2007a). These include osteoporosis, second cancers, declining physical function, heart diseases, obesity and diabetes (Ganz, 2005).

1.5: The challenges faced by a breast cancer survivor

As the number of survivors with long overall or disease-free survival periods increase, their long-term health issues, is an impending public health concern. Survivorship includes multifaceted issues (both medical and psychosocial) and challenges faced by the survivor, as a part of their diagnosis and treatment. (Institute of Medicine and National research council, 2006)

The focus of the cancer physician will always be on the treatment effects, symptoms of recurrence, or a second cancer, at the same time, the survivor will be more concerned about restriction daily activities when they experience hot flashes, weight gain, numbness of arms, memory loss, lack of confidence and, about exploring options to cope up and move forward (D’Souza et al., 2021). In addition, threat of recurrence of cancer, stigma from the society, job related issues , financial burden may also pose challenges to a survivor(Aziz, 2007a).

1.6: Why should we study breast cancer survivorship?

Cancer survivorship is emerging as a separate entity in cancer continuum (McCabe et al., 2013), and the care of a cancer survivor does not end with completion of treatment, but also extended beyond, for recognising and tackling the long term and late sequele of cancer treatment. The issues of the ever increasing breast cancer survivor population can no longer be ignored (Ganz, 2003). Prevention or early detection of a spectrum of medical and psychosocial issues, can help in improving the survivors quality of life (Aziz, 2007a). In India, breast cancer in itself is largely an understudied group, data on survivorship is very limited, and utilisation of registry data for survivorship research is also very few (D’Souza et al., 2021; Kaur et al., 2018). Knowledge regarding the psychosocial issues of long term survivors such as anxiety, depression, loss of employment, fear of recurrence, body image concerns, financial issues are limited and it needs to be studied(Aziz, 2007a). Survivorship research is mainly from high income countries, and the results may not be similar to low income countries, as the challenges experienced by these survivors will be influenced by their sociocultural backdrop (Knaul et al., 2020). Understanding the breast cancer survivorship experiences of this population, is pivotal in formulating culture specific policy plans for the empowerment and improvement of their quality of life (Knaul et al., 2020). Studies conducted among breast cancer survivors were used internationally for understanding research priority areas and for formulating survivorship care plans by ASCO (American Society for Clinical Oncology) (Runowicz et al., 2016), National Cancer Institute(NCI) (Gallicchio et al., 2021), Breast Health Global Initiative(BHGI) (Ganz et al., 2013), and National Comprehensive Cancer Network(NCCN) (Denlinger et al., 2017).

1.7: How are the issues of breast cancer survivors addressed

There are evidenced based guidelines on treatment of different cancers, but very few guidelines are available for the long term follow up of survivors. National comprehensive clinical network (NCCN)(Denlinger et al., 2017, 2018; Sanft et al., 2019) , ASCO (Runowicz et al., 2016), The Breast Health Global Initiative(Ganz et al., 2013) have published international survivorship care guidelines on the follow up care of breast cancer patients. These guidelines include screening and management of issues on long term effects of treatment such as chemotherapy induced toxicities, anxiety, depression, cognitive function, fatigue, pain, sexual functions, body image concerns and healthy lifestyles. (Runowicz et al., 2016).

1.8: Initiatives/interventions around the globe for breast cancer survivorship care

Survivorship care is provided in a few countries and they use a variety of models for post treatment care such as those led by oncologist, by primary care physicians, nurses, shared care approaches, and multidisciplinary survivorship clinics (Mollica et al., 2020). As per ASCO guidelines, the areas suggested for breast cancer survivorship care plans include: surveillance for recurrence, screening for new cancers, assessment and management of physical and psychosocial long term and late effects of breast cancer treatment, health promotion and care coordination (Runowicz et al., 2016). Uses and impact of survivorship care in different parts of the world were assessed through Randomised Controlled Trials(RCT) and non- RCT using published guideline templates or computerised programs, and were reported to be useful with regard to psychosocial wellbeing, health related quality of life, and physical symptoms (Joshi et al., 2021). Studies among survivors of breast cancer has led to an understanding of the issues and challenges faced by these women. Based on this understanding, various interventions for improving life of survivors were initiated around the world (Duncan et al., 2017; Reeves et al., 2014). Various studies focusing on the effect of aerobic exercise in improving bone strength, physical fitness and quality of life in breast cancer survivors (Dieli-Conwright et al., 2018), cognitive behavioural therapy for insomnia (Savard et al., 2005), telephonic psychoeducational interventions to improve quality of life (Ashing and Miller, 2016), education, counselling, pharmacological and behavioural interventions for managing menopausal symptoms and its effect on quality of life (Ganz et al., 2000) in breast cancer survivors were found in the literature. Interventions targeted to improve health outcomes in survivors have shown positive effects in most of the trials(Mollica et al., 2020).

1.9: How is survivorship studied around the world

To study the issues and challenges faced by the survivors, whether it be post treatment manifestations or psychosocial distress or social issues, it is important to identify a defined population of survivors (Ganz, 2003). Various methods were used to study survivors and they are mentioned below. The survivors were identified from the Los Angeles SEER registry, in a study conducted on Non-Hodgkin's Lymphoma, for understanding the experiences and health outcomes among those who completed two to five years of treatment. Here, data were collected retrospectively from medical records and a cross sectional study was conducted among the survivors through mailed questionnaires (Arora et al., 2007). Similarly, Danish registry was used for a study on self-reported work ability among cancer survivors (Carlsen et al., 2013). Hospital based cross sectional studies for understanding the psychosocial issues, quality of life (Purkayastha et al., 2017), and qualitative studies (Binsha et al., 2020; Kaur et al., 2014; Knaul et al., 2020) to explore survivorship experiences were conducted in India and Mexico. A study conducted in Netherlands using surveys to compare work ability of breast cancer survivors at base line and nine months, recruited the study participants through social media, websites and video clips (Boelhouwer et al., 2022). Childhood Cancer Survivor Study is a large retrospective cohort study that assessed health outcomes and mortality in a longitudinal follow up of 5-year survivors (Suh et al., 2020). The American Cancer society study on cancer survivors is the largest prospective long term follow up study of a cohort of survivors identified from the state cancer registry (Stein et al., 2006). Another method is through surveys like the National Health Interview Surveys(NHIS) in USA(Hewitt et al., 1999).

1.10: Problem statement

Breast cancer is the most common cancer among females. Due to the increasing facilities for early diagnosis and treatment, and increasing life expectancy, the five-year survival rate of women with breast cancer is increasing around the world. Hence, there is an alarming increase in this population globally. Cancer care of breast cancer patients does not end at treatment completion. The post treatment survivors living through and beyond, experience psychosocial and physical hardships even after getting cured. Survivorship experiences among breast cancer is a nascent subject, which need to be explored further in terms of their ability to work and perform their day-to-day activities with minimal anxiety and depression. The present study is a retrospective cohort which first studies the data of the survivors based on the Hospital Based Cancer Registry of the year 2016 from a Tertiary Cancer Centre in northern Kerala and subsequently follows them up after six years in 2022.

Aim of the study is to study survivorship among breast cancer survivors from HBCR of a Tertiary Cancer Centre in Northern Kerala.

1.11: Objectives:

Taking the above facts into consideration, the following objectives were formulated for the present study:

Primary objectives:

1. To describe the profile of breast cancer patients based on the Hospital Based Cancer Registry (HBCR) of the year 2016 from a Tertiary Cancer Centre.

2. To study the post-treatment effects of breast cancer patients in the HBCR of 2016 from a TCC after six years of follow-up in 2022

3. To explore their survivorship experiences

4. To study policy associated with the survivorship of breast cancer in Kerala.

Secondary objectives:

1. To study awareness level regarding breast cancer among survivors
2. To study the help-seeking behavior among breast cancer patients in HBCR of 2016 from a Tertiary Cancer Centre.

1.12: Brief overview of chapters:

The research conducted for the fulfilment of these objectives is sub-sectioned to chapters. Chapter one provides an overview of the burden of breast cancer, the concept of cancer survivor and cancer survivorship, the issues faced by a breast cancer survivor, challenges in survivorship research, the need and necessity of studying the survivorship experiences of women with breast cancer and the objectives of the study. Chapter two of this thesis reviews the existing scientific literature on evolution of the concept of survivorship, issues faced by breast cancer survivors, importance of survivorship research in breast cancer, studies on survivorship around the world, approaches and designs used, role of cancer registry in survivorship research, gaps in the survivorship research and the rationale for the study. Chapter three describes the study designs and detailed methodology of various phases of the study. Chapter four reports the findings of the quantitative and qualitative components of the study. Chapter five discusses the findings of the study and compares it with existing literature. Chapter six summarises and concludes the research.

LITERATURE REVIEW

Chapter 2

Literature review

"The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly but also to map the middle ground of survivorship and minimize its medical and social hazards" Dr. Fitzhugh Mullan.

2.1: Introduction

As per the definition given in the introductory chapter- a 'cancer survivor' is a person who is diagnosed with cancer and lives beyond. A person who is treated for cancer, post-treatment completion, a is considered to have conquered the disease. It is also considered that his/her life will be normal again. The post-treatment life for breast cancer patients is not free of problems. There is literature on studies related to various post-treatment long-term physical and psychosocial issues of breast cancer survivors. Existing literature on survivor, survivorship, and their challenges are presented in this chapter.

2.2: Cancer survivor and survivorship

In the early years, when cancer was considered incurable, the word 'survivor' was used for the family members who lost a dear one to cancer, while in 1980, the term was used directly to refer to the patient and his psychological and medical aspects (Marzorati et al., 2017). The problems of this population remained unrecognised by the world, until a Paediatrician and cancer survivor, Dr. Mullan expressed his experiences as a cancer patient, and popularised the word 'cancer survivor' over 'cancer victim' (Marzorati et al., 2017). Dr. Mullan described survivorship as having an active phase, extended and permanent phase. This created a movement among the scientific community, and in 1986 a cancer advocacy organisation, the National Coalition for Cancer Survivorship (NCCS) was formed in USA, which included survivors, health providers, and representatives from other organisations along with Dr. Mullan (Rowland, 2007), to deal with the range of survivorship issues. From the pre-existing definition of 'cancer survivorship', as being alive for five years after cancer treatment, to that phenomenon, starting immediately after diagnosis and remaining to the end of life, whatever the prognosis, was established by NCCS (Rowland, 2007). It recognised survivor as an individual, not a patient, their needs, and not only the treatment (Marzorati et al., 2017). NCCS also played an important role in the establishment of the Office of Cancer survivorship by NCI (National Cancer Institute, 2022). Various definitions were given by different organisations, as there was no consensus regarding the point at which a patient becomes a survivor. There is no unique definition of survivor or survivorship, moreover, description differs between nations, which led to suggestion that context specific operational definitions would be adequate (Khan et al., 2012). The report *From Cancer Patient to Cancer Survivor: Lost in Transition*, published by the Institute of Medicine in 2006, was a major breakthrough in the evolution of survivorship, and it also laid down guidelines for survivorship (Aziz, 2007b).

Table 2.1 gives the existing definitions of 'survivor' available in literature

Table 2.1: Definitions of 'survivor'

Reference	**Definition**
(National Coalition for Cancer Survivorship, 1986)	A cancer patient is a survivor from the moment of diagnosis and for the balance of his or her life, regardless of the ultimate cause of death. Family and care givers are included
(National Cancer Institute, 2022) (Institute of Medicine and National research council, 2006)	In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life. The term is used to describe a population with a history of cancer.
(Twombly, 2004)	The individual with cancer diagnosis, family is not considered in the definition
(Department of Health, Macmillan cancer support and NHS improvement, 2010)	Any one living following a diagnosis of cancer, which includes, those undergoing primary treatment, those who are in remission, those who are cured and those with active or advanced disease
(Bell and Ristovski-Slijepcevic, 2013)	Someone who has had cancer

Table 2.1 ctd.

References	Definition
(Surbone and Tralongo, 2016)	Patients who have lived 3–5 years from diagnosis, or end of treatment, with no evidence of disease at present
(Sanft et al., 2019) (NCCN)	An individual is considered a survivor from the time of diagnosis, during and immediately after treatment, and through the balance of his or her life
(Ganz et al., 2013) BHGI	Persons post treatment, after surgery (6 months of curative treatment)

It is noted that the NCCN, NCCS, NCI-Office of cancer survivorship, and IOM agree that a person is called a survivor from the time he/she is diagnosed with cancer. Most of the guidelines by ASCO and NCCN are for adult cancer survivors who have completed treatment, family/caregivers are not considered at present. (Sanft et al., 2019).

The term ‘survivorship’ has also evolved over the years beginning from Dr Mullan in 1985. Various descriptions of survivorship are found in literature, depending on the cancer diagnosed, patient perspectives, research initiatives and policy initiatives (Khan et al., 2012). The table 2.2 gives the descriptions of ‘survivorship’ in literature.

Table2.2: Definitions/ descriptions of ‘survivorship’

Reference	Definition/descriptions
(Mullan, 1985)	Described as the three different seasons of the year 1) acute phase which starts from diagnosis to the completion of initial treatment which is dominated by treatment related issues 2) Extended phase which begins with the completion of treatment, and mainly deals with the consequences of treatment 3) Permanent phase, when the chances of cancer recurrence decreases, but long-term effects of treatment remain
(Livestrong foundation, 2016)	Cancer survivorship is the experience to live with, through and beyond cancer.
(National Cancer Institute, 2022)	Describes survivorship phases to include those diagnosed with early cancer, those diagnosed with or progressed to metastatic cancer or those diagnosed with or progressed to end stage cancer

Table 2.2 ctd.

(Miller et al., 2008)	‘Transitional Survivorship phase’ reflecting the transition from active treatment to surveillance and the emotional, social, and medical adaptations that occur. ‘Permanent survivorship’ including survivors who are (1) cancer-free but not free of cancer, (2) cancer-free but continue to have psychosocial, medical, financial, or legal sequelae, (3) develop second cancers (4) develop cancers that are secondary to the initial treatment
(National Coalition for Cancer Survivorship, 1986)	The experience of living with, through and beyond a cancer diagnosis

Today, the most widely used definition describes cancer survivorship as a process that begins from the point of diagnosis, and continues through the balance of the patient’s life; and focusses on medical, psychological and legal needs of the patient, which demands care from the beginning. Dear and near ones impacted by the cancer diagnosis are also included (Marzorati et al., 2017).

2.3: Global studies on cancer survivorship

Ever since survivorship research gained importance, studies were conducted in different parts of the world to understand survivorship issues. Studies among survivors of lung cancer (Perloff et al., 2019), testicular cancer (Fung et al., 2019), adolescent and young adult cancer (Yarbrough, 2021), childhood cancer (Suh et al., 2020), prostate cancers and cervical cancers (Knaul et al., 2020), and breast cancer were conducted around the world.. When compared to other cancers, in addition to the long-term health effects, breast cancer survivors have issues related to bodily changes and symptoms due to early menopause as this disease occurs more in younger women.

2.4: Importance of survivorship research in breast cancer

2.4.1: Breast cancer- a growing health problem

Breast cancer in itself has become an important public health priority with more than two million cases globally in 2020, and a predicted rise to three million in 2040. The incidence rates were above 80/lakh in transitioned countries to less than 40/lakh in transitioning countries (Arnold et al., 2022). Prevalence for breast cancer, is the highest among all women cancers in the United States of America (Merrill et al., 2000). Asia accounts for 39% of all breast cancer cases in the world (Fan et al., 2015). China and India followed by Japan are the leading Asian countries in breast cancer incidence (64%). More than 50% of breast cancers were diagnosed below 50 years of age in Asian countries. (Sharma, 2021). India also witnesses a growing burden of breast cancer (IARC, 2020). Over the years a transition is also noticed in the cancer cases in India, with gradual decline of infection related cancers and a upsurge in lifestyle related cancers such as breast and colon cancer(Smith and Mallath, 2019). In a comparison study in Asia, the 5-year survival of breast cancer was above 80% in China, Japan, Korea, Israel, and Qatar and below 70% in Malaysia and India (Fan et al., 2015) and 91% in USA (Miller et al., 2022).

With the alarming rise to four million breast cancer survivors in USA in 2022, and advancements in early detection and treatment, breast cancer survivors will still increase in the years to come (Miller et al., 2022). Breast cancer patients live long after treatment (Miller et al., 2022), and can have long standing side effects which may be reflected as low health related quality of life (Runowicz et al., 2016). Attempts have been made to study the difficulties of breast cancer patients, either due to the disease itself or the treatment.

2.4.2: Side effects of breast cancer treatment

The modalities of treatment available for breast cancer are surgery, radiation therapy, and systemic therapy, including chemotherapy, targeted therapy, and hormonal therapy(Miller et al., 2022). Studies among breast cancer patients who underwent treatment, report that there were side effects for the various modalities of treatment.

Long-term effects are the medical problems that the patient experiences during anticancer treatment and continue even after treatment completion, whereas late effects are the medical problems that become obvious months to years after active treatment. Some of these effects may even overlap (Runowicz et al., 2016).

Table 2.3: summarizes the long-term and late effects of different modalities of breast cancer treatment.

Tab 2.3: The long-term and late effects of breast cancer treatment

Type of treatment	Long term effects	Late effects
Surgery	Body image issues, sexual dysfunction, numbness/ pain/weakness /restricted movements in the arm	Lymphoedema
Radiotherapy	Fatigue, pain, sexual dysfunction, asymmetrical breast volume, lymphoedema, numbness and weakness of upper limb	Breast asymmetry, lymphoedema, shortness of breath, sexual dysfunction, pain, numbness and weakness of upper limb, second primary cancers (lung)
Chemotherapy	Cognitive issues, fatigue, Ovarian failure/ menopausal symptoms, sexual dysfunction, weight gain, Hair loss	Osteoporosis, increased risk of cardiovascular diseases
Hormonal treatment (Tamoxifen)	Hot flashes, Changes in menstruation, Mood changes, increase in triglycerides	Increased risk of endometrial cancer, Increased risk of stroke Osteopenia in premenopausal women
Aromatase inhibitor	Vaginal dryness, decreased libido	Increased risk of osteoporosis and fractures
Targeted therapy (Transtuzumab)	Risk of cardiac dysfunction	
General psychological long term and late effects	Depression. Distress, anxiety, fear of recurrence, fear of pain, End-of-life concerns, loss of sexual function and/or desire, challenges with body image and self-image, relationship and other social role difficulties, return-to-work concerns and financial challenges	

(Runowicz et al., 2016)

The common long term and late physical effects of breast cancer treatment are discussed below:

2.4.2.1: Lymphoedema

Lymphoedema is arm, breast, or chest wall swelling due to block in the flow of lymphatic fluid from the arm and/or breast, leading to retention of fluid (Runowicz et al., 2016). Surgical treatments such as axillary dissection, radiation in the axilla as part of cancer treatment(Rietman et al., 2002), and increased BMI(Body Mass Index) at diagnosis (McLaughlin et al., 2020) are quoted as risk factors for lymphoedema. Depending on the extend, lymphoedema is associated with pain, heaviness, tightness, or restriction of arm movements affecting daily work, social roles, and employment (Denlinger et al., 2018), and a cause for psychosocial distress due to bodily disfigurement in a cancer patient (DiSipio et al., 2013; Gillespie et al., 2018). Majority (90%) presents in the first 24 months of treatment as disproportionate size of the limb (Rockson, 2018). A meta-anlaysis study reported, overall incidence to be 21.4%, affecting every one in five women after breast cancer treatment (DiSipio et al., 2013; Sun et al., 2020), varying from 13.4% to 43% according to the modality of treatment(Deo et al., 2004). Detection through screening and early intervention can act as a preventive measure. (Gillespie et al., 2018).

2.4.2.2: *Fatigue*

Fatigue, a multidimensional symptom, may be due to the disease, its treatment or other comorbid conditions, and is prevalent in all phases of breast cancer continuum; from preoperative through post operative to surveillance phases (Berger et al., 2012). About 43% to 95% reported fatigue during varying periods of treatment (Álvarez-Bustos et al., 2021; Berger et al., 2012). Studies state that pain, depression, insomnia, and cognitive disfunction were also associated with women reporting fatigue which contributed to overall reduction in the health-related quality of life (QOL) (Ganz and Bower, 2007). Even though fatigue decreases over time in a breast cancer patient, it was much more than the general population even after many years(Ganz and Bower, 2007).

2.4.2.3*: *Pain

Persistent pain after breast cancer is a complex issue and includes neuropathic pain post chemotherapy(Alhazmi et al., 2021), post-surgical pain, post radiotherapy pain, and generalised pain, and is associated with reduced quality of life, higher levels of anxiety, depression (Juhl et al., 2016; Wang et al., 2018), and restriction of daily activities (Rietman et al., 2002). Breast, chest wall, shoulder and arm were the main sites of pain (Juhl et al., 2016). Reviews among breast cancer patients, reported varying amounts of pain during different stages of treatment. The prevalence varied from 21% to 29.8% after three months of treatment (Wang et al., 2018), 12%-51% at one year (Rietman et al., 2002), and 38.3% after three years of treatment (Juhl et al., 2016).

2.4.2.4*: *Menopausal symptoms and sexual health

Healthy women attain menopause at an average age of 51 years(range 45 to 55 years) (Denlinger et al., 2017). Premature menopause, a consequence of cancer treatment, is found to have adverse health outcomes in young breast cancer patients, and causes disturbing symptoms like hot flashes, and vaginal dryness(Rosenberg and Partridge, 2013), which is much higher compared to healthy controls (Ganz et al., 1998). Chemotherapy induced premature menopause is responsible for osteoporosis in 80% of women, hot flashes/night sweats in 50% to 70%, loss of sexual desire in 23% to 64%, and dyspareunia in 35% to 48% of women (Runowicz et al., 2016). Premature menopause has a major impact on sexuality and intimacy, with sexual problems and infertility more prevalent among young women(Ganz et al., 2003).

2.4.2.5*: *Cognitive issues

Cognitive issues like decreased memory, difficulty in concentration and difficulty in executing various functions are reported in 35% to 65% of women, irrespective of age, either due to the disease or treatment (Ganz et al., 2003). It was as high as 75% in women during treatment, and 35% after treatment, and may be associated with other treatable conditions like insomnia, depression or fatigue (Runowicz et al., 2016).

2.4.2.6: ***Psychosocial issues***

Psychosocial issues in breast cancer patients include distress, anxiety, and depression (Runowicz et al., 2016). Anxiety and/or depression can develop at any stage of breast cancer treatment from diagnosis to the terminal phase of illness, and can adversely affect the quality of life (Abraham and Kallivayalil, 2021). A variety of factors related to cancer or it’s treatment is likely to be associated with depression/anxiety, including the type and stage of cancer, prognosis, treatment (chemotherapy), and comorbidities (Niedzwiedz et al., 2019; Zhang et al., 2022). In a cross-sectional study conducted among breast cancer patients in Malaysia, anxiety and depression was 31.7% and 22.0%, six years after treatment(Hassan et al., 2015). In Indian studies, the prevalence of depression was 21.2%- 46% , and was associated with overall poor quality of life (Purkayastha et al., 2017; Thakur et al., 2019). Young age and low socioeconomic status were associated with anxiety, and unmarried status was associated with depression (Hassan et al., 2015; Shankar et al., 2016), and both were related to the stage of disease (Shankar et al., 2016). Social issues, such as living alone, having young children, and being of younger age (Denlinger et al., 2014), pain, job loss (Wondimagegnehu et al., 2019),concerns for family, fear of death or disease recurrence, body image changes, disturbances in sexual life, and social exclusion(Abraham and Kallivayalil, 2021), were also related to psychosocial distress among survivors. A study conducted in Ethiopia shows that every one in four breast cancer patients had depression (Wondimagegnehu et al., 2019). All said, research on the mental health problems and challenges faced by long term cancer survivors are still scarce(Breidenbach et al., 2022).

2.4.2.7: ***Functional impairment***

Functional impairment is defined as limitations due to a condition or its treatment that prevent people from carrying out certain functions in their daily life (Bijker et al., 2018). Work ability is one of the main factors affecting the process of return to work in breast cancer survivors (Musti et al., 2018)Work ability in breast cancer survivors, though higher than that in other cancers, is much less compared to general population (Lindbohm et al., 2012), and is affected by fatigue, cognitive issues, and low social support (Boelhouwer et al., 2022; Vandraas et al., 2022), chemotherapy, lack of work support, and comorbidity (Lindbohm et al., 2012). Impairment in physical and emotional functioning was associated with low work ability and poor work related outcomes in these women (Bijker et al., 2018). In another study 43.5% reported reduced work ability, when compared to the period before diagnosis, the associated factors being marital status and mastectomy(Musti et al., 2018). It was found that, after breast cancer treatment only 57% continued the same work (Schmidt et al., 2019a). Unemployment is more in breast cancer survivors in comparison with the general population (Maunsell et al., 2004) and is associated with job adjustments like reduced work hours(22%), working for lower salary, which results in reduced earnings (Schmidt et al., 2019a; Syse et al., 2008). Better productivity and quality of life among employed survivors compared to the unemployed, underlines the importance of work in this population (Boelhouwer et al., 2022). Work ability, in breast cancer survivors has hardly been studied in Asia(Ho et al., 2018).

2.4.2.8: Second cancers

Second cancers can occur in survivors due to biological character of the primary cancer, genetic susceptibility, exposure to risk factors or secondary to the effects of cancer treatment (Denlinger et al., 2014; Ganz, 2003). In breast cancer survivors, the risk of endometrial cancers is more for those on Tamoxifen (Miller et al., 2022)

2.4.2.9: Positive outcomes

Studies reported that the cancer experience may result in a wide range of positive outcomes as well. A sense of empowerment, gratitude, stronger family bonds (Denlinger et al., 2014), greater appreciation for life, feeling of an enhanced sense of meaning and purpose to life, better ability to cope up with stress and other life challenges as a result of their cancer experience (Adorno et al., 2018; Bower et al., 2005) were all reported by survivors.

As a part of improving the wellbeing of the breast cancer patient, who is now believed to have a normal life expectancy, there is a need to understand the experiences and the challenges faced by this population, which sum up to their survivorship.

2.5: Studies on breast cancer survivorship

Continuation of the post treatment effects, along with some unique issues related to their cancer journey, poses challenges to a survivor, as they move on from the acute treatment to the extended phase of survivorship(Aziz, 2007b). Most women consider the conquering of disease as survivorship, while others state that it has increased their awareness about life and death and has broadened their outlook of life (Documèt et al., 2012). The increase in number of survivors has raised concern about their health, and led to many studies around the world on various issues of survivors. The diagnosis of breast cancer and its treatment were associated with significant adverse influences on physical and mental health, quality of life, and the economic status of the patient and her family, especially in Indian settings, where women's health is not considered a priority (Srivastava and Kumar, 2022).

Literature search in PubMed and Google scholar was conducted using the following MeSH terms for search "Breast Cancer", "Survivor", "Breast cancer survivorship", "treatment effects", 'Late effects"," anxiety", "depression", psychosocial distress", "physical effects", "survivorship experiences", "lived experiences", "body image", "sexuality", "stigma", "needs", "menopausal symptoms", "reproductive issues', "supportive care needs", "work ability", "work related".

Table 2.4 gives the studies on breast cancer survivors around the world and the issues/problems studied.

Table 2.4: Literature on breast cancer survivorship

	Author and country	**Time since diagnosis**	**Factors studied**
1	(Zucca et al., 2012) Australia (registry based)	5-6 years	Insomnia, fatigue, cognitive function, pain
2	(Kaur et al., 2018) India (Kaur and Jain, 2018)	1-5 years	Fatigue, pain, cessation of menstruation, loss of sexual desire, Quality of life
3	(Dsouza et al., 2018) South India	6 months	Arthralgia, anxiety, pain, depression, cognition, skin/

			hair/ nail problems, hot flashes, arm swelling and vaginal dryness
4	(Singh–Carlson et al., 2013) South Asia	3-60 months	Fatigue, fear of recurrence, sexuality issues
5	(PV Gadgil et al., 2015) Urban India	3months to 19 years	Arthralgia, anxiety, pain, Depression, cognitive, hot flashes, lymphedema, vaginal dryness, social issue
6	(Cho et al., 2014) Korea (Smedsland et al., 2022) Norway	Not mentioned	Sexual wellbeing, sexual activity
7	(Binsha et al., 2020) South India	2 years	Support system, fear of recurrence
8	(F and Sc, 2016) USA	2-19 years	Implications of survivorship
9	(Michelle S Barthakur et al., 2016), India (Thakur et al., 2022), India (Bower et al., 2005)	Not mentioned 4 months to 5 years 1-10 years	Post traumatic growth- stronger relationships, spirituality Perceptions of positive meaning
10	(Schmidt et al., 2019b)Germany (van Maarschalkerweerd et al., 2020) Netherlands	1 to 5 years 5-10 years	Return to work (RTW) and QOL
11	(Knaul et al., 2020) Mexico	1 to 6 years	Physical/sexual issues, stigma, financial, family support, body image
12	(Patel-Kerai et al., 2015) UK	5 to 32 years	Lived experiences of immigrants, importance of support groups, body image concerns
13	(Nyblade et al., 2017) Karnataka	Not mentioned	stigma
	Table ctd.		
14	(Hassan et al., 2015) Malaysia, (Yi and Syrjala, 2017) USA, (Abraham and Kallivayalil, 2021; Carreira et al., 2018; Greer et al., 2011; Hinz et al., 2016; Inhestern et al., 2017; Tsaras et al., 2018) (Breidenbach et al., 2022) (Vahdaninia et al., 2010)	Various	Psychosocial (Anxiety and depression) Quality of life

	(Thakur et al., 2021) India (Thakur et al., 2019) India (Tsai et al., 2020) (R. et al., 2023)-metareview (Hodgkinson et al., 2007),Australia (Purkayastha et al., 2017),Kerala (Rajendran et al., 2021), India (Srivastava et al., 2015),India (Sharma et al., 2015) India (Prakash Saxena et al., 2018), India		
15	(Ganz et al., 2003) USA	2-10 years	Reproductive issues and late health effects
	(Schultz et al., 2005) USA	>5 years	Menopause
16	(Khajoei et al., 2023), Iran		Supportive care needs
	(Singh–Carlson et al., 2013), S Asian		Follow up care plans
17	(Barthakur et al., 2017) India		Body image and sexuality
18	(Michelle S. Barthakur et al., 2016) India	6 months	Survivorship experiences Needs of survivors
	(Daniel et al., 2022) India	On treatment	
	(Kaur et al., 2018), India (Ashing-Giwa et al., 2004) (Rosenberg et al., 2022) (Srivastava and Kumar, 2022), India (Chiaranai et al., 2022), Thailand		
	(Maggi et al., 2022), India		Community perceptions,
	Table ctd..		
19	(Ganz and Bower, 2007)USA (Ruiz-Casado et al., 2021) (Bower et al., 2006; Meeske et al., 2007) (Kaur, 2022), India		Fatigue
		1-5 years	

20	(Musti et al., 2018) (Carlsen et al., 2013; Lindbohm et al., 2012) Danish (Vandraas et al., 2022), Norway (Boelhouwer et al., 2022), Netherlands (Maunsell et al., 2004)	Various 8 years	Perceived work ability Work situation after breast cancer
21	(Tompkins et al., 2016) London	1 year	Unmet needs
22	(Alexander et al., 2019) India	7 years	Impact on patient and family

The studies were done among the survivors beginning from 3 months to 19 years of follow up, and covered various aspects of survivorship such as long term and late effects of treatment, psychosocial issues, work ability, stigma, quality of life, unmet needs, and impact on family. Majority of the studies were qualitative, as this method help to understand breast cancer survivorship experiences in a deeper perspective (Cho et al., 2014). The quantitative studies assessed the quality of life of the survivor (Hodgkinson et al., 2007; Purkayastha et al., 2017) or measured levels of anxiety, depression, work ability, quantity of life, fatigue, pain using various tools. In addition to this, other factors studied were sexual wellbeing (Cho et al., 2014; Singh–Carlson et al., 2013), stigma (Nyblade et al., 2017), body image (Patel-Kerai et al., 2015), financial issues (Knaul et al., 2020), and fear of recurrence (Binsha et al., 2020). Large population based follow up studies based on registry were mainly from high income countries (Carlsen et al., 2013; Lindbohm et al., 2012; Maunsell et al., 2004). Others recruited survivors either from hospital outpatient departments or specialized follow up clinics. Some of the studies dealt with single issues like anxiety, depression, quality of life, frequency of late effects, fatigue, pain, and lymphedema and few dealt with multiple issues.

Studies from India were mainly hospital-based cross sectional studies on anxiety, depression, quality of life, late effects of treatment; qualitative studies on stigma, post traumatic growth, body image, sexuality. The studies were mainly from

Karnataka (Alexander et al., 2019; Michelle S. Barthakur et al., 2016; Dsouza et al., 2018), Kerala (Abraham and Kallivayalil, 2021; Binsha et al., 2020; Daniel et al., 2022; Prakash Saxena et al., 2018; Purkayastha et al., 2017), Tamil Nadu(Rajendran et al., 2021), North India(Kaur et al., 2018; Thakur et al., 2021). None of the studies utilized cancer registry. The studies from India were among survivors in varying periods of follow up and there were a few studies where period of follow up was not mentioned.

2.5.1: Approaches and designs used

Studying problems of cancer survivors has many challenges related to the enrolling of study participants(Ganz, 2003). Participants/cohorts for studies on survivors were recruited from cancer registries, hospital outpatient departments or specialised clinics(Ganz, 2003). Cancer registries were used for enrolling participants in a population based study conducted on survivors of Hodgkin's lymphoma in the United states(SEER cancer registry)(Arora et al., 2007), study on work ability of survivors utilized the Danish cancer registry(Carlsen et al., 2013), and in prospective long term follow up study of cohorts from state cancer registry by American Cancer Society (Stein et al., 2006). Retrospective cohort studies like The Childhood Cancer Survivor Study for studying mortality trends in childhood survivors utilised clinical treatment trial data base for participant recruitment (Suh et al., 2020). The American Cancer Society Studies of Cancer Survivors (ACS SCS) also has longitudinal (SCS-I) and cross-sectional (SCS-II) components which was designed for assessing the physical and psychosocial impact of cancer on long-term cancer survivors (Smith et al., 2007).

In hospital based cross sectional studies on breast cancer survivors, participants were recruited from hospital registries, hospital outpatient departments or specialised clinics (PV Gadgil et al., 2015; Kaur et al., 2018; Purkayastha et al., 2017; Singh–Carlson et al., 2013; Zucca et al., 2012) or snowballing techniques were also used (Rajagopal, 2022).

Studies were qualitative, quantitative, mixed studies or reviews. Majority were qualitative studies(Barthakur et al., 2017; Michelle S Barthakur et al., 2016; Binsha et al., 2020; Dsouza et al., 2018; F and Sc, 2016; Knaul et al., 2020) or quantitative studies(PV Gadgil et al., 2015; Kaur et al., 2018; Singh–Carlson et al., 2013; Zucca et al., 2012) assessed the quality of life, anxiety, depression, frequency of physical effects etc. Few used mixed method design(Alexander et al., 2019) and few were reviews (Srivastava and Kumar, 2022).

Studies on survivorship were mainly based on the high income countries and hence results cannot be generalised (Ganz, 2003). Studies from major cancer registries failed to represent minorities, rural and those from poor socioeconomic status (Stein et al., 2006). Majority of studies recruited survivors who vary in time since diagnosis, making comparisons difficult. Studies enrolling cohorts of survivors who were followed up longitudinally were even fewer (Smith et al., 2007). As mentioned above, many of the studies were from United States of America, South Asia. Korea, Ethiopia, Mexico, Germany, Australia and UK and a few from developing countries like India. The studies from India were mainly qualitative and a very few on the late effects of treatment and quality of life.

Cancer registries are recognised as the most efficient method of identifying cohorts of survivors, who can be followed up at varying intervals for comparisons studies at various phases of the cancer continuum(Smith et al., 2007).

2.6: Cancer registry in survivorship studies

For studies on cancer, there are cancer registries in most of the countries of the world which capture the incident cases (Ganz, 2003). Cancer registries were used to study incidence, time trends, projections of cancer, cancer survival statistics, in epidemiological research, for evaluating programs for prevention, early detection, and cure, and can also be used for follow up studies for outcome in specific cohorts (Parkin, 2006). Cancer registries can serve as an important source for enrolling large cohorts of survivors even with relatively less common cancers (Arora et al., 2007).

The world’s first registry, which reported data of a defined population, collected from multiple sources was at Hamburg in 1926. With the starting of the Connecticut tumour registry, a Population Based Cancer Registry was established in USA in 1941, followed by the Danish registry in 1942 (Chatterjee et al., 2016).

In India, the Indian Council of Medical Research (ICMR) initiated the National Cancer Registry Programme (NCRP) in 1981, and established a network of Population Based Cancer Registries (PBCR) and Hospital Based Cancer Registries (HBCR)(Chatterjee et al., 2016). The first PBCR in India, was initiated in Bombay in 1963 which provided reliable data on the cancer incidence in Bombay. Most of the HBCRs are in regional cancer centres and hence provide data on cancer in those hospitals and give information on cancer patterns in their service areas (Chatterjee et al., 2016). PBCR's can also be used to examine rates standardized by age, age-specific incidence, sex ratios, rates in different ethnic groups, migrants, time trends, and survival(Banydeen et al., 2015). The most recent estimates of India's cancer burden reported in the GLOBOCAN database were created by extrapolating data from several regional PBCRs, with limited rural representation.(Smith and Mallath, 2019). Indian registries cover only 10% of the population (Mathur et al., 2020). Passive follow up by linkage to vital statistics data and active follow up by contacting patients are the methods followed (Allemani, Matsuda, Di Carlo, et al., 2018).

In Northern Kerala, the HBCR collects data on all cancer patients who are registered in the TCC in that particular year. The PBCR in Malabar Cancer Centre is known as the Malabar Population Based Registry and provides incidence and mortality data base from northern districts of Kannur and Kasargode (from Kerala) and Mahe (Union territory of Puducherry). For this data is collected from 298 sources which includes cancer hospitals, secondary and tertiary care hospitals, nursing homes, diagnostic laboratories and death registration offices. Thirteen cancer registries from Kerala provided data to ICMR for the report published in 2021(ICMR-NCDIR, 2021). In Kerala, only 4.6% of the total population is covered by PBCR's (Jayalekshmi et al., 2006).

The lack of clinical data in some of the registries and decreased extent of population coverage is often a setback in the representativeness of the data (Parkin, 2006). It was reported that cancer registries cover only 21% of the world population, the larger and populated countries having very few with uneven urban-rural distribution(Parkin, 2006). Only one fifth of the Asian countries have population based cancer registries, of which only four of them have 100% population coverage (Fan et al., 2015; Yoo, 2010). Low quality of registry data is an important challenge for the middle-resource Asian countries such as, India (Mathew et al., 2011), China, Malaysia, Turkey, and Iran (Fan et al., 2015).

Leveraging the existing registries and expanding the existing data sources by collecting additional data required for survivorship studies was endorsed by National cancer institute survivorship workshop along with studies on long term survivors more than five years for a better understanding of the spectrum of late effects(Gallicchio et al., 2021).

2..6.1: Challenges in enrolling survivors from registry

As stated above, one of the challenges is regarding enrolment of the participants (Ganz, 2003). Lost to follow up and drop outs are another issue. Non accessibility of treatment facilities, non-affordability of cancer medicines, socioeconomic factors like stigma, family responsibilities (Huang et al., 2023), recurrence of cancer, affinity towards traditional medicines all lead to treatment drop outs (Doval et al., 2020). Another issue addressed in studies were the challenges in contacting women from the registry due to incorrect addresses and unanswered calls (Howards et al., 2021). Research on cancer survivors were mostly conducted at major cancer centres located in urban areas, which leads to exclusion of the low socioeconomic, and hard-to-reach populations.

2.7: Survivorship care services around the world

The recommendations of the Presidents cancer panel and Centre for Disease Control and prevention in 2004 laid the foundation for the IOM report *From cancer patient to cancer survivor; lost in transition* in 2006 (Institute of Medicine and National research council, 2006). Survivorship care plans have been endorsed by professional and voluntary health organisations (Jacobsen et al., 2018), and guidelines for survivorship care are laid down by leading oncology care providers like ASCO (McCabe et al., 2013; Runowicz et al., 2016), NCCN (Denlinger et al., 2017, 2018; Sanft et al., 2019), BHGI (Ganz et al., 2013) for multiple cancers or for specific cancers like breast cancer. ASCO have also suggested interventions for the various post treatment effects including bone health and obesity and health promotion strategies(Melisko et al., 2016).

A review about the existing services for survivorship care available among 27 countries of the world, show that only 45% of the 22 countries with a National Cancer Control Program addressed survivorship care. Most of the Low Middle-Income Countries (LMIC)focus on treatment and not follow up care, and no survivorship care plans are reported in 14.3% of LMIC including India. In India, oncology care based follow up is the practice in a few cancer centres; the main areas focused include physical effects, recurrence, new cancers, with no efforts on psychosocial surveillance or care(Mollica et al., 2020).

Studies were also conducted regarding needs and expectations from survivorship care in places where they exist, and found that care should not be tailor made to fit all, rather should be person centric, and equally satisfying for all including minorities and ethnic groups (Tompkins et al., 2016)

2.8: Gaps in survivorship research

Most of the long term and late effects occur in long time survivors. Despite this, most research has focused on cancer patients early in the trajectory of care(Aziz, 2007b; Daniel et al., 2022). Most of the symptoms are experienced by patients collectively, still majority of studies focus on a single symptom (Kaur, 2022; Schultz et al., 2005; Zucca et al., 2012). Most of the long-term studies have been conducted at major cancer centres, located in urban areas, and often suffer from an under representation of minority, poor, rural, and other hard-to-reach populations. Even fewer studies have enrolled cohorts of survivors who are followed longitudinally through the survivorship continuum (Smith et al., 2007).

Studies from India on long term survivors are scarce and they often deal with the psychosocial distress like anxiety and depression and most of the studies are from urban areas. Studies on work ability among breast cancer survivors from Asia are scarce, except one study conducted at Singapore which studied association between work ability, anxiety and depression in breast cancer survivors in varying years of follow up (one year to ten years) (Ho et al., 2018). However, studies on survivors especially breast cancer survivors are very few in India (Kaur et al., 2018). Studies from Kerala are mainly hospital based cross sectional studies. There are no studies from Kerala based on long term follow up of a cohort of breast cancer survivors based on registry as noted from literature review. There are no studies from India where survivorship was studied in the dimensions of work ability, depression and anxiety in a cohort of breast cancer survivors from the registry, followed up after six years.

2.9: Rationale

Breast cancer is the leading cancer among women and is a growing public health concern. Early detection and successful cure have resulted in an increase in the number of breast cancer survivors living for many years after treatment. Life after cancer is challenging for the survivor, as they have to face with long term health issues due to the treatment, other issues relating to womanhood and challenges related to their sociocultural background. Although definitions are inconclusive, the frequency in the use of the term 'survivorship' in literature denotes its significance (Marzorati et al., 2017). Most studies on cancer survivorship focusses on early survivorship phase (the period between diagnosis and two years after treatment completion). Since study on long-term follow up studies on survivors based on registry, was not done in Kerala, we decided to conduct the study on breast cancer patients included in the HBCR of the year 2016, who have completed six years post treatment. It is noted that were no studies on work ability among breast cancer survivors from India. Further, studies on survivors from rural area is practically non-existent in India. Further our TCC is located in a rural area.

The need for survivorship research is now largely accepted around the world to bring up solutions in increasing the quality of life of these women. The survivorship experiences of these woman will give the much required guidance to the healthcare professionals in making policies and planning guidelines to support these women in their journey through cancer (Binsha et al., 2020). Survivorship research is needed to guide and update health care providers, who may be unaware about the late effects of cancer treatment faced by these long term survivors, as these women may not be under oncology care as they age (Ganz, 2003).

METHODOLOGY

Chapter 3

Materials and methods

This chapter includes the study design, description of the phases of the study and its organisation, description of the study setting, the tools used for data collection in each phase, the validity and reliability of the tools, the sample size for each phase, inclusion and exclusion criteria for each phase, data collection methods, data analysis for each phase, and ethical considerations.

3.1. Study design

The present study followed a retrospective cohort design.

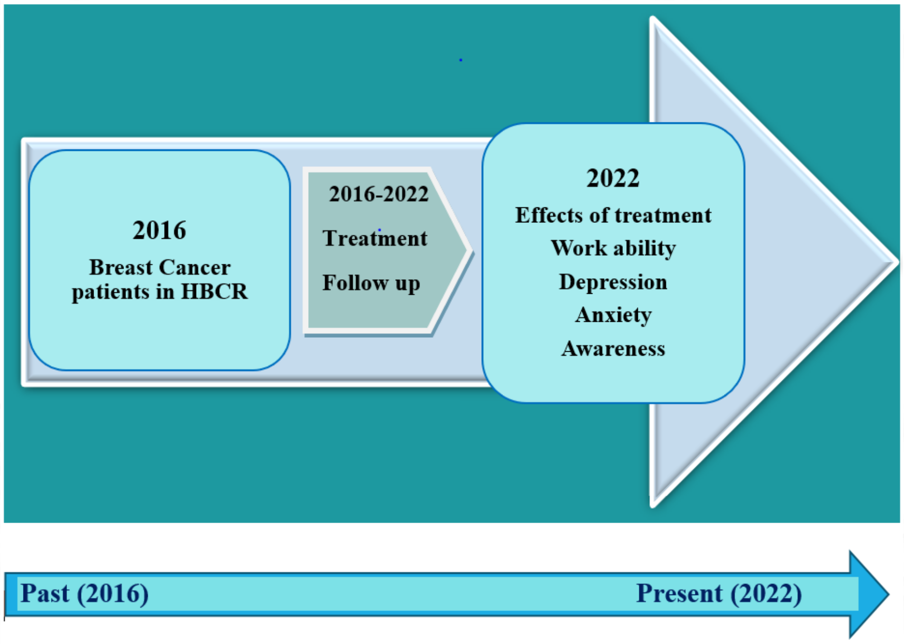


Fig 3.1: Visualisation of the study design

In this type of study design, the eligible subjects are identified retrospectively from pre-existing data, a cohort is organised, and the investigator starts with the variables in the baseline and traces these individuals forward to measure the outcome during the period of follow-up (Euser et al., 2009; Ranganathan and Aggarwal, 2018).

The cohort here consisted of female breast cancer patients from the HBCR of a Tertiary Cancer Centre (TCC) of the year 2016. These patients were registered in the TCC in 2016, had undergone treatment in 2016-17 and are presently under annual follow-up. The data of all these patients (n=534) were entered in the hospital records during their first visit and subsequently during each treatment and follow-up visits. The data was also included in the HBCR. Their sociodemographic details and data regarding their initial condition in 2016 were collected retrospectively from their hospital records. This was done utilising the Unique Hospital Identification Number (UHID) of the patients registered in 2016, obtained from the Department of Cancer Registry of the TCC with necessary permission and consent. These patients were traced after six years in 2022, and a follow-up survey was conducted to have a better understanding of their survivorship experience. The factors studied were the treatment-related long-term health effects, work ability, depression, anxiety, and awareness about breast cancer among the survivors at the time of the follow-up survey. The barriers faced by the survivors during the initial help seeking period were also studied.

3.2: Organisation of phases of the study:

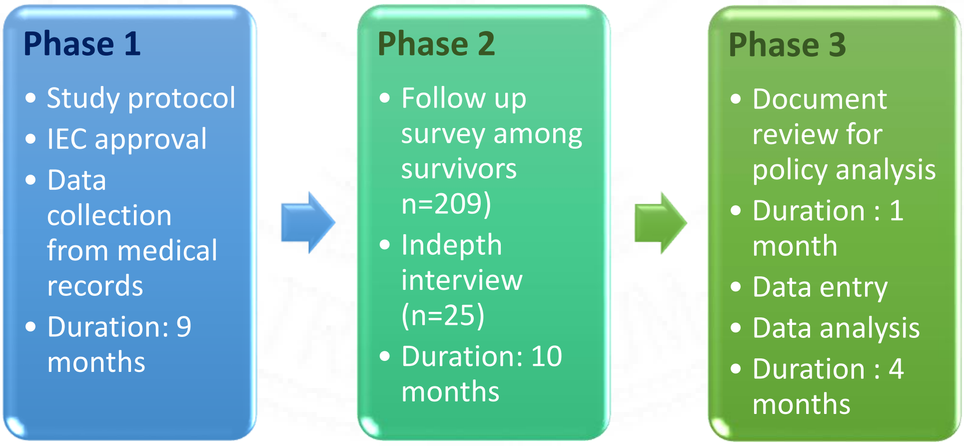


Figure 3.2: **The organization of phases of the study**

3.2.1: Phases of the study

The study was conducted in three phases:

Phase 1 included the collection of sociodemographic and other data of the patients included in the HBCR of the TCC of the year 2016, retrospectively from the medical records. The patients were traced after six years in 2022, and Phase 2 included a follow up survey on various aspects of the survivors along with conduct of in-depth interviews from survivors for capturing their survivorship experiences. Phase 3 included, a review of policy documents on breast cancer control and survivorship.

3.2.1.1: Phase 1: Collection of registry-based data

Hospital-based cancer registry of a particular year included all cancer patients registered in the TCC during that year. Hence, the HBCR of 2016 included all cancer patients registered in the TCC during the period from January 2016 to December 2016, irrespective of whether they were diagnosed in 2016 or any other previous year. In this study, we included only the female breast cancer patients from the HBCR of the year 2016 (n=534). The HBCR core form of Indian Council of Medical Research (ICMR), was utilised regularly by cancer registry for abstracting data from medical records. The variables in this form were utilised in this study for collecting data from the medical records of the patient. The records were accessed by utilising the UHID obtained from the Department of Cancer Registry. Permission for access to the Cancer Registry and patient data was obtained from the Director, and the Head of the Department of Cancer registry of TCC. The data collection tool was adapted from the HBCR core form of ICMR. All breast cancer patients who registered in the TCC as per HBCR of the year 2016 were included This phase of the study was conducted from October 2021 to March 2022, after obtaining approval from the Institutional Ethics Committee of both the TCC and SCTIMST.

3.2.1.2: Phase 2: Follow-up survey with quantitative and qualitative methods

This phase included a cross sectional survey and in-depth interviews conducted among survivors. The follow up survey was conducted among these survivors during the study period beginning in January 2022. Inclusion criteria-All female breast cancer patients who were diagnosed in 2016, and registered in the TCC as per HBCR of the year 2016 and traceable in 2022.

Exclusion criteria- Those who could not be contacted, those who did not give consent, those who died, those who could not comprehend either due to old age or due to mentally challenged conditions, those who had a known history of anxiety or depression or were on medications for the same.

Subsequent to Phase 1, those who were included for the Phase 2 were listed down to be followed up. After excluding the patients who were lost to follow up, those who died and those who were not traceable, the number of patients available for Phase 2 study was 209. These survivors were followed up for the purpose of determining their present status, categorised as those who are currently disease free, those who were living with disease recurrence, and those who succumbed to the disease.
Quantitative part: During the follow up survey, tool was administered for recording sociodemographic details, the long-term and late effects of breast cancer treatment, work ability, anxiety, depression, and their present level of awareness regarding breast cancer symptoms and risk factors, and the barriers faced by these women during their initial help-seeking journey. As the survivors in our study have completed more than five years after treatment, they are presently coming for follow up only once in a year.

Qualitative part: This phase also had a qualitative part, which collected information to understand the survivor experience of those who are cured; the challenges of those who are having recurrence of disease at present. In-depth interviews were conducted among selected participants from the 209 survivors using an interview schedule. The quantitative and qualitative data were mainly collected when the survivors came for follow-up in the outpatient department (OPD). The period of data collection was 10 months.

3.2.1.3: Phase 3: Document review

The objective was to analyse the documents associated with breast cancer policy in Kerala to understand the importance given to breast cancer, cancer registry and survivorship. Government documents were collected and reviewed using a checklist. This phase was completed in four months.

3.3: Study setting

The setting of the study was a TCC in northern Kerala. The centre is an autonomous institution under the Government of Kerala, providing comprehensive cancer care to seven northern districts of Kerala and adjoining districts of Karnataka, Tamil Nadu, and the Union Territory of Puducherry. Around 30 to 40 new cancer patients and 500 to 600 patients on follow-up and treatment reported at the institution every day. Various Government schemes which provide financial assistance to cancer patients can be availed by patients who undergo treatment here. The institution has a state-of-the-art cancer diagnosis, treatment, and rehabilitation facilities and is actively involved in cancer prevention activities in the community. The institution has HBCR and a Malabar Population-Based Cancer Registry (MPBCR). The MPBCR collects information from Kannur, Kasaragod, and Mahe districts. The published MPBCR (*MPBCR Annual Report 2015*, 2020)and HBCR report (*HBCR(Annual Report 2016)*, n.d.) for the year 2016 show 634 and 534 female breast cancer patients respectively. The retrospective collection of data of the study subjects for Phase 1 was done with the support from Cancer Registry Department and Medical records division of the TCC. The follow up survey tool was administered mainly when survivors came to the outpatient department (OPD) of the TCC for routine follow up. A room near the OPD was used for data collection considering privacy issues. Some of the data collections were done at places other than the TCC, based on the choice and convenience of the study participants.

3.4: Data collection tools

3.4.1. Tool for collecting data based on cancer registry

This tool was used for extracting data from medical records. The data collection form was adapted from the HBCR core form of ICMR. This form was used by the Cancer Registry department for extracting data from patient records. The questions related to breast cancer in the core form alone were included in the data collection form, in addition to the socio demographic variables. Sociodemographic variables were age, sex, place of residence, location (urban/rural), marital status, mother tongue, religion, education, and occupation and job.

Variables specific to the current problem included in the tool were; The date of registration which is the date when the patient was registered in the TCC extracted from the medical records of the patient; The date of first diagnosis which is the date of histopathological confirmation obtained from laboratory reports; The year of diagnosis for those who were diagnosed in any year other than 2016; Diagnostic status at the time of registration which states whether the cancer was confirmed microscopically or only suspected, clinically or radiologically; Method of diagnosis whether by histology, radiologically(mammogram, ultrasound); diagnostic methods (Cytology, histopathology of primary site, histopathology of secondary site), Primary site and morphology of primary site, secondary site(regional lymph nodes or distant metastasis), clinical stage at diagnosis as per AJCC (American Joint Committee on Cancer)staging system 8th edition; treatment before registration(whether treatment was taken from any other centre before coming to the TCC and type of treatment taken); Performance status on presentation at TCC in order to quantify patients general wellbeing and activities of daily life (able to perform daily activities, restricted in physically strenuous activity but able to carry out light work, ambulatory and capable of self-care, confined to bed or chair for more than 50% of waking hours, totally confined to bed or chair) ; Whether cancer directed treatment was given at TCC and work abilitytype of treatment given, type of surgery; date of treatment initiation at TCC, Date of treatment completion at TCC; whether treatment was complete or incomplete, reasons for non-treatment if any, performance status at 6 months post treatment, date of last contact at TCC as given in the medical records, date of death as recorded in the medical records of the patient.

3.4.1.2. The staging system in breast cancer used in the study

The clinical stages of the breast cancer described and utilised for analysis in this study were based on the eight and most recent edition of AJCC. This is the gold standard reference in cancer staging; the anatomy-based and histology-based original Tumour Node Metastasis (TNM) staging system, with the addition of evidence based changes in the classification for decision on treatment and for assessing prognosis (Giuliano et al., 2017)

Table 3.1: TNM staging system for breast cancer (AJCC 8th edition)

Category	**Criteria**
1.Tumor	
Tx	Primary tumor cannot be assessed
T0	No evidence of primary tumour
Tis	Ductal carcinoma in situ
T1	≤20 mm in greatest diameter
T1mi	Tumour ≤1mm
T1a	Tumour >1mm but ≤5mm in greatest dimension
T1b	Tumour >5mm but ≤10mm in greatest dimension
T1c	Tumour >10mm but ≤20mm in greatest dimension
T2	Tumour >20mm but ≤50mm in greatest dimension
T3	Tumour >50mm in greatest dimension
T4	Tumour any dimension with direct extension to chest wall /skin /ulceration /macroscopic nodules.
T4a	Extension to chest wall with invasion
T4b	Ulceration/ ipsilateral microscopic nodules/ peau d' orange
T4c	Both T4a and T4b
T4d	Inflammatory carcinoma
2. Node	
Nx	Regional lymph nodes cannot be assessed
N0	No regional lymphadenopathy
N1	Metastatic movable ipsilateral level1, level 2 axillary nodes
N2	Metastases to ipsilateral level1or 2 axillary nodes which are fixed/ ipsilateral internal mammary nodes
N2a	Mets to ipsilateral level1, 2 axillary nodes fixed to one another/other structures
N2b	Metastases to internal mammary nodes in the absence of axillary nodes
N3	Metastasis to ipsilateral infraclavicular node with/ without level 1/2 axillarynodes
N3a	Metastatic to ipsilateral infraclavicular node
N3b	Metastases ipsilateral internal mammary nodes and axillary nodes
N3c	Metastasis to ipsilateral supraclavicular node

Table ctd.	
3. Metastasis	
M0	No clinical or radiographic evidence of distant metastasis
M1	Distant metastasis detected by clinical/ radiological means/histologically proven
4. **Stage**	
Stage 0	Tis N0 M0
Stage 1A	T1 N0 M0
Stage 1B	T0NImiM0, T1 NImiM0(mi-micro metastasis)
Stage 2A	T0 N1M0, T1N1M0, T2N0M0
Stage 2B	T2N1M0, T3N0M0
Stage 3A	T0N2M0, T1N2M0, T2N2M0, T3N1M0, T3N2M0
Stage 3B	T4N0M0, T4NIM0, T4N2M0
Stage 3C	Any TN3M0
Stage 4	Any T, Any N, M1

3.4.1.3: Operational definitions of selected variables used in the study

Table 3.2 elaborates operational definitions of variables used in this study.

Table 3.2: Operational definitions of selected variables and time points

Variable /time point	**Operational definition**
Hospital registration number	The unique identification number provided to the patient at the hospital where all further patient related information will be linked to.
Date of registration	The date on which the patient first reported at the TCC and enrolled him/her as a patient (in this study it is from January 1st 2016 to December 31st 2016)
HBCR of 2016	Hospital Based Cancer Registry which contains data of all cancer patients who registered in the TCC from January 1st 2016 to December 31st 2106
Date of first diagnosis	As given by European network of cancer registries in “Hierarchy for defining date of diagnosis” (in our study, the date of pathology report (laboratory report is taken).
Occupation	As reported by patient
Age at diagnosis	The age as given in patient records, categorized to <50 years and ≥ 50 years
Sex	Being male, female, or transgender
Education	As codes given by ICMR.1. illiterate 2. literate (no formal school education) 3. Primary (1st to 5th std) 4. Middle (5th to 8th std) 4. Secondary (8th to 12th std) 5. Collage and above. Here it is further categorized as (1) Below 5th standard (2) 5th standard and above

Rural/ Urban	The districts are divided into geo political units- Panchayaths (described as rural) and Municipalities/Corporation (described as urban).
Marital status	Those who are married and cohabiting (married) Those who are widowed, divorced or separated(others)
Time between diagnosis and registration	Calculated as time between date of registration and date of first diagnosis. Categorized as within one month and more than one month.
Stage of disease	Extend of the disease at the time of diagnosis as per the TNM staging (Table 3.1).
Performance status	A score that estimates patients' ability to perform certain activities of daily living (WHO codes)
Treatment given at RI	Treatment given from TCC
Incomplete or partial treatment	Treatment was taken at TCC, but part of treatment was taken (1) from elsewhere either before registering at TCC or (2) after initial treatment at TCC they were referred to a convenient centre as requested by patient or (3) stopped treatment as patient could not tolerate/died/went for other systems of treatment as they wished.
Date of commencement of treatment	The date of starting cancer directed treatment at TCC as given in patient records
Date of completion of treatment	The date of completion of treatment at TCC, as given in patient records
Time between registration and treatment start at TCC	Calculated as time between date of registration and date of starting cancer directed treatment as given in patient records (Categorized as within 1 month, between 1 and 2 months, more than 2 months)
Date of last contact	Date of last follow up at hospital as per patient records
Date of death	As in patient records (death either at TCC or documented date as 'informed by bystander over telephone')
Survivor	In this study survivor means all those breast cancer patients registered in TCC in 2016.
Lymphedema	Swelling of the arm as a result of a blockage of the lymphatic fluid from the arm and/or breast, leading to retention of fluid.
Cognitive impairment	Includes problems with attention, executive function, memory and processing speed
Fatigue	Subjective feeling of tiredness, weakness, and/or lack of energy.
Numbness/tingling of arms	Neuropathic symptoms which are common after treatment especially with chemotherapy
Risk factor	A factor responsible for causing a particular condition or disease

3.4.2: Data collection tool for follow up survey

This instrument was used to collect data from survivors who were under follow up in 2022, regarding the various aspect like long-term health effects of treatment, work ability, levels of anxiety and depression, present awareness among survivors regarding risk factors and symptoms of breast cancer, and barriers faced by them during the initial help-seeking process before diagnosis. In addition to the sociodemographic factors, and details regarding the present status of survivors (present stage, date of recurrence, and treatment status wherever applicable) the questionnaire also consisted of:

3.4.2.1: Physical long-term and late health effects of treatment among survivors.

The long-term effects depend on the type, duration, and dose of treatment, the patient's age at diagnosis, the specific type of chemotherapy, and the type of hormonal treatment. The tool was prepared in accordance with published data similar to our study, and discussion with experts in the field of breast cancer treatment and cancer registry department. The guidelines were adapted from breast cancer survivorship guidelines of the American Cancer Society (Runowicz et al., 2016).The Self assessed long term and late effects included were pain, fatigue, lymphedema (fluid retention in the arms causing differences in size of the limb), numbness or weakness of upper extremity, shortness of breath, cardiovascular diseases on treatment, cognitive issues(memory loss, difficulty in concentration, difficulty in executing functions), symptoms related to osteoporosis, weight gain, infertility issues, oral health issues, hot flashes, mood changes, and changes in menstruation. The questions were administered by the PI and answers were recorded as either yes or no.

3.4.2.2. Scale to measure self-assessed work ability among survivors (Work ability Index)

'Work ability' is defined as ability of a worker to perform his/her job with respects to work demands, health and mental resources. Since majority of survivors in the present study were homemakers, we wanted to understand their work ability with respect to their day-to-day work.

3.4.2.2.1: Measurement: The Work Ability Index (WAI) is a valid and well accepted self-report tool developed as a measure of perceived work ability of individuals. It was developed by the Finnish Institute of Occupational Health (FIOH) in 1980, based on the stress strain concept and balance model(Ilmarinen, 2007). It is widely used in studies and is available in 30 languages. Here people can evaluate work ability which is based on their own perception of their ability to work. The instrument covers seven items in relation to work plus a list of diseases. Though initial scale consisted of a long list of 51 diseases ,shortened version with a list of 14 diseases was found to be equally efficient as given by Nübling, M., et al, which is used in this study(Ilmarinen, 2009; Schouten et al., 2015). The seven items include (1) Current work ability compared with their lifetime best(score 0-10); (2) work ability in relation to the demands of the job(score 2-10); (3) number of diagnosed illnesses(score 1-7); (4) estimated impairment due to diseases/illnesses or limiting conditions(1-6); (5) Sick leave taken during the past 12 months(score 1-5); (6) own prognosis of work ability in 2 years' time (score 1-7); and (7) estimate of their mental resources(score 1-4). As majority of our survivors were homemakers, for item number five we specifically enquired "Did you have any day in the last 12 months when you had to be laid down without being able to do your regular work, due to your disease?" and responses were recorded.

The evaluation was based on last 12 months and number of parentheses for each item indicates the scoring range. The scores are calculated according to standard method provided by FIOH. Total score is obtained by adding up score of each item except items 3 and 4 and 7. For question three, diseases diagnosed by a doctor only are assessed. If there are five diagnosed diseases (1 point), four diagnosed diseases (2 points), three diagnosed diseases (3 points), two diagnosed diseases (4 points), one diagnosed disease (5 points), no diagnosed diseases (7 points). For item four, since there is option to make more than one choice, the lowest value is added for total scoring. For item 7, the scores of the three questions are added together and the sum is modified as follows: sum 0–3 = 1 point, sum 4–6 = 2 points, sum 7–9 = 3 points and, sum 10–12 = 4 points. Score ranges from 7 (unable to work) to 49 (full work ability), with further classification into established categories of Excellent (score 44–

49), Good (score 37–43), Moderate (score 28–36) and Poor (WAI ≤27) work ability (Tuomi et al., 1997).

3.4.2.2.2: Reliability and validity of the tool: As per reliability and validity studies, WAI may be treated as internally coherent, very predictive and cross-nationally stable instrument (Adel et al., 2019; de Zwart et al., 2002; Mateo Rodríguez et al., 2021; Radkiewicz and Widerszal-Bazyl, 2005). The tool has been validated in India and was translated to Tamil and Telugu for studies conducted among workers in plantations and quarries of South India (Anbazhagan et al., 2016; Soumyashree et al., 2018). The WAI has been used worldwide to assess work ability in heterogenous cancer patients including breast cancer (Boelhouwer et al., 2022; Carlsen et al., 2013; Lindbohm et al., 2012, 2012; Taskila et al., 2007; van Maarschalkerweerd et al., 2020).

For the present study, linguistic validity for the tool was done using a forward and backward translation methodology. The tool was translated to the local language Malayalam and expert review sought, following which it was back translated to English and compared for clarity in the meaning of the questions and appropriateness of language. A pilot survey among ten survivors was also conducted for assessing the face validity and appropriate corrections made as per suggestions given regarding understandability and clarity of language and difficulties in answering. Reliability was assessed using internal consistency approach. Cronbach’s alpha was calculated and found to be 0.8.

***3.4.2.3. Scale to assess the anxiety level of the survivors (GAD 7)*:** The level of anxiety among survivors is assessed by using the Generalised Anxiety Disorder 7 (GAD 7) scale in this study.

As validated published measurements should be used for uniformity and generalisability, ASCO suggests recommendations adapted from the Pan Canadian Guideline on Screening, Assessment and Care of Psychosocial Distress in adults with cancer. Accordingly, GAD 7 was one of the recommended instruments for screening anxiety among cancer patients and survivors (Andersen et al., 2014). The scale has proven to have good reliability as well as criterion, construct, factorial and procedural validity, as well as found to be valid in primary care and general population. It has been used in a numerous studies among cancer patients and survivors around the world(Carreira et al., 2018; Tsaras et al., 2018) and in India (Shankar et al., 2016; Shunmugasundaram et al., 2021).

3.4.2.3.1.Measurement: A validated, published Malayalam version of GAD 7 freely available for downloading is used here (GAD7_Malayalam for India.pdf, n.d.). For the measurement, symptoms experienced by the patient over the past two weeks is considered. The seven items which describe some of the salient features of GAD include: (1) Feeling nervous, anxious, or on edge, (2) not being able to stop or control worrying, (3) worrying too much about different things, (4) trouble relaxing, (5) being so restless that it is hard to sit still, (6) becoming easily annoyed or irritable, and (7) feeling afraid as if something awful might happen. Evaluation was based on last two weeks. and anxiety severity score were calculated by assigning scores of 0, 1, 2, and 3 to the response categories, of "not at all," several days," "more than half the days," and "nearly every day" for each item. GAD-7 total score for the seven items ranges from 0 to 21. Cut-off points of ≥5, ≥10, and ≥15 represent mild, moderate, and severe levels of anxiety (minimal anxiety (0-4); mild anxiety (5-9); moderate anxiety (10-14); and severe anxiety (15-2) (Spitzer et al., 2006). For evaluation purpose, in our study they are again categorized to "No anxiety" (score<5) and "anxiety" (score≥5) (Prakash Saxena et al., 2018).

3.4.2.4. Scale to measure level of depression (PHQ 9): PHQ 9 was the scale used to assess depression levels in the present study. Patient Health Questionnaire-9 (PHQ 9) (Kroenke et al., 2001), recommended by ASCO(Andersen et al., 2014) is a self-administered depression scale derived from the Primary Care Evaluation of Mental Disorders.

3.4.2.4.1. Measurement: The scale comprises of 9 items, each evaluating the nine Diagnostic and Statistical Manual of Mental Disorders –Fifth edition criteria of depression, rated as "not at all" (0) to "nearly every day" (3). The average sensitivity and specificity was 88%/78% with a cut-off score of 10 (minimum acceptable being 80%/70% for case finding instruments) Pettersson et al., 2015). The nine items include; 1) Little interest or pleasure in doing things, (2) Feeling down, depressed, or hopeless, (3) Trouble falling or staying asleep, or sleeping too much, (4) Feeling tired or having little energy, (5) Poor appetite or overeating, (6) Feeling bad about yourself—or that you are a failure or have let yourself or your family down, (7) Trouble concentrating on things, such as reading the newspaper or watching television, (8) Moving or speaking so slowly that other people could have noticed or the opposite—being so fidgety or restless that you have been moving around a lot more than usual, (9) Thoughts that you would be better off dead or hurting yourself in some way. Evaluation was based on last two weeks, and the total score ranges from 0 to 27.

PHQ 9 was mainly utilised in oncology studies for the diagnostic accuracy in screening for Major Depressive Disorder, rather than characterizing a population of cancer patients who have PHQ 9 identified depressive symptoms (Hartung et al., 2017; Thekkumpurath et al., 2011). The scale has been used in studies on depression in cancer survivors (Götze et al., 2020) and in Kerala, among cancer patients undergoing treatment where a cutoff point above 5 was used (Purkayastha et al., 2017). Cut off points varied from ≥5, ≥7, ≥8 or ≥10 and were used in various studies(Hartung et al., 2017; Purkayastha et al., 2017; Thekkumpurath et al., 2011). When compared with diagnostic status by mental health professionals, PHQ 9 scores less than five almost always signified the absence of a depressive disorder, whereas scores from five to nine had either no or subthreshold depression (Kroenke et al., 2001). Hence, a cut-off point of five is used in this study for categorising those with absolute no depression and those with mild /moderate/severe depression for analysis (Prakash Saxena et al., 2018). A validated, published Malayalam version of PHQ 9 freely available for downloading is used here(PHQ9_Malayalam for India.pdf, n.d.).

3.4.2.4.2. Validity and reliability: A validated, published Malayalam version of PHQ 9 and GAD 7 freely available for downloading is used in this study (GAD7_Malayalam for India.pdf, n.d.; PHQ9_Malayalam for India.pdf, n.d.).

For the present study, a pilot survey among ten survivors was also conducted for assessing understandability and clarity of language and difficulties in answering. No corrections were suggested. For reliability regarding internal consistency, Cronbach's alpha was calculated and found to be 0.78 and 0.73 for GAD7 and PHQ 9 respectively.

3.4.2.5. Scale to measure awareness level of breast cancer: The tool also consisted of questions to assess the present awareness regarding risk factors and symptoms of breast cancer, and barriers faced during health seeking process The questions were adapted from the 'Breast CAM' - Breast module of the breast cancer awareness measure developed by Cancer Research UK, King's College London and University College London in 2009 (BreastCAM.pdf, n.d.; Linsell et al., 2010). Breast CAM was reported to be a robust measure for use in breast cancer awareness surveys in general population (Linsell et al., 2010). The tool was translated to various languages including South Indian language, Kannada in a study conducted in South India (Baburajan et al., 2022).

3.4.2.5.1. Validity and reliability: This is a validated questionnaire for measuring the knowledge about symptoms, and risk factors and understanding the barriers faced during the help seeking process in breast cancer. Psychometric studies have evaluated the properties of the Breast CAM in heterogenous populations around the globe and all of them have reported satisfactory validity and reliability (Abdou et al., 2020; Htay et al., 2020; Liu et al., 2020). The psychometric properties, the test retest reliability, and construct validity was found to be good and sensitive to changes in awareness due to interventions (Linsell et al., 2010). For this study, the tool was translated to Malayalam using the forward and backward translation method. The backward translated English version and the original version were compared for conceptual and cultural aspects. Expert consultation was done for content validity. A pilot survey was also conducted among 10 women which included patients(n=5), bystanders (n=3) and lady staff (n=2) for assessing the face validity. They were asked to read the questions and provide suggestions regarding understandability, the clarity of language used and to report problems faced in answering. Appropriate corrections were made as per suggestions. The responses of the help seeking based questions was recorded as 'always', 'sometimes', 'no' and 'don't know'. The responses for the risk factor-based questionnaire were recorded as 'strongly disagree', 'disagree', 'not sure', 'agree' and 'strongly agree'. For evaluation purposes the responses were clubbed together as 'disagree', 'not sure' and 'agree'. For questionnaire on awareness regarding symptoms of breast cancer the responses were given as 'yes' and 'no'.

3.4.3: Tool for collecting qualitative data-the interview schedule

Qualitative data were collected through in-depth interviews with breast cancer survivors who were presently free of disease and those who were presently living with disease recurrence.

3.4.3.1: Interview schedule for collecting survivorship experiences of survivors who were disease free at present

The interview schedule was to assess the survivorship experiences of the survivors. Steps in the preparation of interview schedule:

1. *Expert review*: Discussion was done with Doctorial Advisory Committee members and experts in the field of Oncology, Biostatistics, Cancer registry Department and Social scientist.

2. *Literature review*: A literature review was conducted to list the various factors which can explain the present status of the women, challenges faced, help seeking barriers, social issues, stigma. An inventory was created from the previous questionnaires identified in the literature review. The inventory was discussed and feedback sought from experts.

3. *Translation:* Questionnaire was developed in English and translated to local language Malayalam. Face validity was done by administering it to 10 women survivors and their opinion and suggestions regarding understandability of questions and clarity of area specific language used was sought. Whatever corrections were suggested were done. For further clarity and uniformity regarding questions, the investigator herself conducted the interviews. After getting consent and greeting the

participant, questions regarding their follow up, present status, their views on survivorship, whether they were back to work and challenges faced, the other challenges faced during the trajectory, stigma, attitude of friends and family, the good things and worst things they faced in their life post disease, the support they received, the moral support which they could provide to newly diagnosed patients as a survivor and their thoughts on this were asked. They were also asked regarding their ideas and opinion on more facilities and services which they considered were required during their follow up visits. There was not much difficulty experienced in understanding the questions and providing answers. The interview schedule ended with the thanking of participants.

3.4.3.2: Interview schedule for collecting survivor experiences of survivors who are on treatment for disease recurrence at present

The steps in the preparation of the interview schedule were similar to that detailed above. The questions were largely based on their present disease condition. The participants were patients now who were taking treatment, as they had recurrence of disease or progression of disease to an advanced stage. Questions on their present disease, treatment, their thoughts on life, 'how they managed the financial crises, and 'why they thought the disease came back', were asked. As the patients were in a very sensitive phase of life, the interviews were conducted with great caution. No difficulty was observed in understanding the questions and answering them. The patients were willing to take part in the study. Out of the ten patients, two were interviewed over telephone, as the interview was not possible while they were having chemotherapy in the hospital. They gave consent and suggested a convenient time for interview over telephone. The interviews ended by thanking the participants.

3.4.4. Check list for document review

A check list was prepared on the basis of which the document review was done. It consisted of questions to identify the key institutions and organizations involved in cancer/breast cancer control in the state, functions and responsibilities of the stake holders, for identifying initiatives and measures taken for early breast cancer diagnosis, existing guidelines for cancer follow up and survivorship plans, importance given to cancer registry in the documents, goals and objectives laid down with respect to breast cancer survivorship plans if any.

3.5. Phase 1: Collection of registry-based data

This phase of the study was for retrospective collection of data of the cohort of study participants from the patient records. This data was be used for evaluation of registry-based data. The variables in the data collection form were adapted from the HBCR core form of ICMR.

3.5.1: Sample size

The data of all the female breast cancer patients registered in the TCC in 2016 available in the HBCR of same year was included. Hence sample size was 534.

3.5.2: Sample selection procedure

All female breast cancer patients who registered in the TCC during the period from January first 2016 to December 31st 2016 and available in the HBCR of the year were included in the study for initial analysis. This cohort included not only breast cancer patients who were newly diagnosed in 2016 (either in the TCC or elsewhere), but also those diagnosed in any other year (from 1991 to 2015) and reporting for posttreatment follow-up or investigations like mammogram or for adjuvant treatment such as radiotherapy and chemotherapy or for treatment of metastasis or for a second opinion regarding treatment.

Inclusion criteria: All female breast cancer patients in HBCR of 2016

3.5.3: Data collection techniques

Data of female breast cancer patients registered from January first 2016 to December 31st 2016 and included in the HBCR of the year was collected. The UHID of all those registered in 2016 was obtained from the cancer registry department. Utilising this UHID, the patient records were collected from the medical records division of the TCC. Data was collected on the basis of the variables in the HBCR Core form of ICMR under National Cancer Registry Program.

3.5.4: Study variables

Sociodemographic variables include age, sex, place of residence (urban/rural), marital status, mother tongue, religion, education, and occupation.

Variables specific to the current problem include date of registration, date of first diagnosis, year of diagnosis, Time between diagnosis and registration, diagnostic methods, stage at diagnosis, pathomorphological details, treatment before registration, date of treatment initiation at TCC, time between registration and treatment, type of treatment taken, type of surgery, time from treatment start to completion, whether treatment was complete or incomplete, reasons for non-treatment if any, performance status at 6 months post treatment, date of last contact, date of death.

3.5.5 Data analysis

Data was scrutinized for incompleteness and responses which were inappropriate. Following this, data was entered into appropriate statistical software. Each respondent was given a unique identification code. Variables were also coded appropriately. Recoding was done wherever needed. After data cleaning, analysis was done by using a statistical software with data management and analysis tools. Frequencies and proportions were used to describe categorical variables. Mean and standard deviations were calculated for continuous variables which were normally distributed (checked by the Kolmogorov Smirnov test (p-value >.05)). Bivariate analysis of categoric variables was performed with the help of contingency tables and Chi square statistics or Fischer’s exact test. Significant alpha level was taken as .05 for Chi-square and Fisher’s exact tests.

3.5.5.1 Background characteristics of study population

3.5.5.1.1 ***Univariate analysis*****:** Characteristics of the study population were summarised using appropriate statistical tools. Age was described in terms of means and standard deviations and after categorisation into age groups, it was described as frequencies(percentages). Frequencies and proportions were calculated for most of sociodemographic variables like sex, religion, place of residence, level of education, marital status, and job. Other variables like year of diagnosis, disease profile, method of diagnosis, time between diagnosis and registration and treatment profile were also given as frequencies and proportions.

3.5.5.1.2 ***Bivariate analysis*****:** Relevant variables which may exhibit possible interactions were selected to find out empirical associations between those variables. For this analysis, the data of all the female breast cancer patients who were newly diagnosed in 2016 was utilised instead of analysing a heterogenous group. Four hundred and thirty-seven women were diagnosed as new patients in the year 2016. Hence sample size used here is 437. For this purpose, cross tabulations and Chi square test of independence were done between sociodemographic factors and disease factors. Wherever the contingency table contained a count less than five, the Fischer's exact test was done.

3.6: Phase 2: Follow up survey among survivors in 2022

This phase included a quantitative component (follow up survey) and qualitative component (in-depth interviews with the survivors).

3.6.1: Description of the cohort from 2016 to 2022

For assessing the participants to be included in the follow up survey, there is a need to understand the changes in the size of the cohort since registration of the patient in 2016 to follow up in 2022. Deaths occurring every year and those dropping off from the routine follow up for various reasons brought changes in the size of the cohort.

Fig 3.3 illustrates the changes in size of the cohort over the years. As described in **section 3.5**, the initial cohort consisted of all female breast cancer patients registered in 2016 in the TCC. The sample size in 2016 was 534.

The figure given above shows the changes in the size of the cohort from 2016 to 2022. The number of female breast cancer patients who registered in the hospital for treatment in 2016 was 534. This included the breast cancer patients who were diagnosed for the first time in 2016 (n=437), and those who were diagnosed in the previous years, between 1991 and 2015 (n=97). All of them registered in the TCC for the first time in the year 2016. From both the categories there were lost to follow up and deaths during the period from 2016 to 2022.

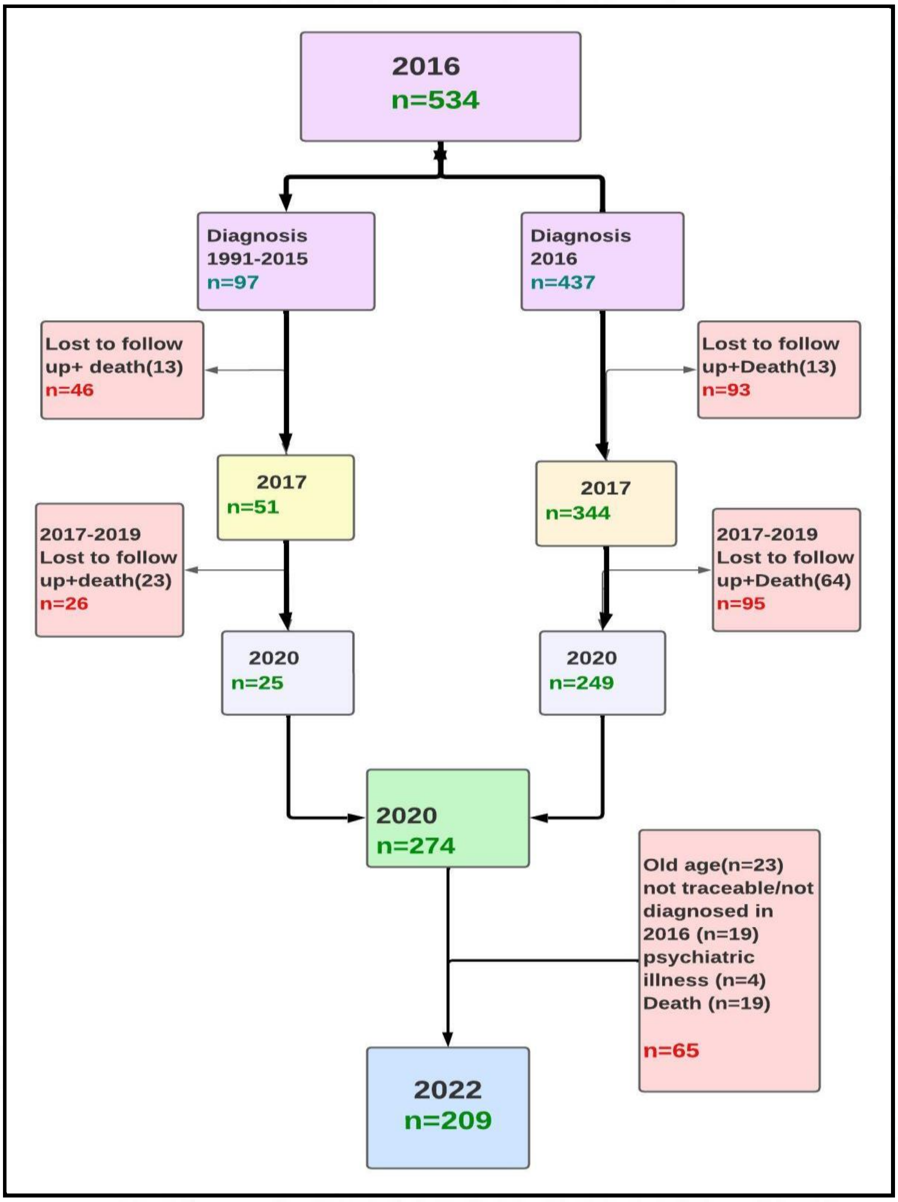


Figure 3.3: Changes in the size of the cohort from 2016 to 2022

One hundred and thirty-nine women visited the hospital only on the day of registration and did not report for a second time. They did not take further treatment from the hospital. They had either come for second opinion regarding treatment or they went to health facilities of their choice for treatment or died. After accounting for lost to follow up and death, the number of survivors in 2017 was 395. A total of 121 women either lost to follow up or died between 2017 to 2019. After subtracting this, the number of women in the beginning of 2020 were 274.

As the COVID pandemic had brought changes in the regular follow up pattern, most of the women could not visit the hospital after 2020, and their disease status documentation was not available in the records. Hence, we decided to follow up all those survivors who were documented to be present in 2020 as per records. As per exclusion criteria which will be detailed subsequently, n=65 women were excluded and 209 survivors were included in the follow up survey in phase 2. A total of one hundred and thirty-two study participants were documented as ‘died’ in the hospital records. Their death either occurred at the TCC or date of death was documented in hospital records after their relatives confirmed it through telephonic messages.

3.6.2: Follow up survey among survivors in 2022

Follow up survey was done to assess various outcomes among survivors who were under follow up in 2022.The outcomes measured included the long term and late health related side effects of breast cancer treatment presently among survivors, their present work ability and factors associated with it, present levels of anxiety and depression among survivors and the associated factors, and present level of awareness regarding symptoms and risk factors of breast cancer among survivors. We wanted to assess whether going through the entire journey of diagnosis and treatment had brought about changes in their awareness about breast cancer. It was also of interest to know about their help seeking behaviour during the initial phases and the barriers faced for understanding their survivorship. The tools prepared for the purpose as described in section 3.4.2 was used for collecting data in this phase.

3.6.3: Sample size

Cohort size from 2016 to 2022 is demonstrated in **Figure 3.3** and described in section 3.6.1. The number of study participants who were under follow up after 2020 were 274. After excluding dropouts and deaths, and fulfilling the requisites of the study, 209 survivors were included in the study.

3.6.4: Sample selection procedure

3.6.4.1: Inclusion criteria

All female breast cancer survivors who were traceable in 2022 and who gave consent for the study.

3.6.4.2: Exclusion criteria

Those who could not be contacted, those who did not give consent, those who died, those who could not comprehend either due to old age or due to mentally challenged conditions, those who had a known history of anxiety or depression or were on medications for the same.

3.6.5: Data collection techniques

The hospital records of 534 study participants who were included in the HBCR of the year 2016, were scrutinized for recent documentation of their disease condition. In cases where recent documentation was not seen, the contact numbers of those who had their last follow up in the years 2020 or 2021 were noted and contacted. This was done because most follow ups had become irregular during the COVID pandemic. From the calls /hospital records, the women's present status was assessed (regarding their traceability and whether they were alive). They were also asked regarding the place and time of meeting which was convenient to them. Help from the medical records division was also sought for getting information on the survivors who were given dates for follow up in the hospital on a particular day. For those women, data collection was done on the day of follow up. The Principal Investigator (PI) also tried to contact those who did not report on the date of follow up. They were called at least five times on different days, different times of the day and on all numbers available from the records, before considering them as non-traceable. Medical records were also searched for any change of address. Majority of the data were collected during their follow up visits in the TCC. Some women consented to come for data collection to the Associate Centres for early cancer detection operated by the TCC, as it was accessible to them. Data were also collected by visiting their houses or any nearby places of their choice as per their consent. Few data had to be collected over telephone during the initial phases of data collection, due to the restrictions in travel imposed by COVID pandemic from October2021 to January 2022 (n=46). Their consent forms were sent by post for signature. The tool was administered by the PI herself, to those who consented to participate in the study and met the requisite criteria. It was done either during follow up visits at TCC or in the community at any place and time convenient to the patient or if willing, in one of the three rural Associate centres for early cancer detection under the TCC. For those coming to outpatient department (OPD) for follow up, the tool was administered in a room near the OPD giving adequate privacy to the participants. Care was taken that there was nobody else in the room except PI during data collection. Those who wanted their bystander along with them were allowed to do so. In case of those participants who were under treatment at the time, care was taken to administer the tool only if they were comfortable. In others, the interview was postponed to their next visit. Data was collected using the tool mentioned above in sections 3.4.2 and 3.4.3. The investigator herself administered the questionnaire to all participants taking time to explain the questions and clarify their doubts if any. This phase was done from December 2021 to October 2022.

3.6.6: Study variables

The sociodemographic variables include age, place of residence, educational level, marital status, occupation and parity and employment status.

Variables related to the present disease status include, Present vital status, Present stage, Type of surgery, Details of recurrence and whether on treatment now, and any Comorbidity.

Variables related to long term and late effects of breast cancer treatment include Fatigue, Pain, Lymphoedema, Numbness /weakness of upper limbs, cognitive issues, osteoporosis like symptoms, Weight gain, Hot flashes, Mood changes and, Treatment induced menopause, symptoms related to osteoporosis, oral symptoms.

Variables associated with Work Ability, were part of the WAI scale. They are described in detail in **section 3.4.2.2.**

Variables associated with GAD 7 (**section 3.4.2.3)** scale for anxiety and variables associated with PHQ 9 scale for depression is also described in detail (**section 3.4.2.4).**

Variables associated with assessing awareness levels regarding risk factors like "past history of breast cancer", "family history of breast cancer", "having no children", "early menarche", "late menopause", "being overweight", "more than 70 years of age", and "decreased physical activity". There was also an open-ended question which asked about "Any other risk factors which you could think about". Variables associated with assessing awareness levels regarding symptoms of breast cancer include "change in nipple position", "indrawn nipples of recent onset", "pain in the breast", "puckering /dimpling of skin", "bleeding/discharge from nipple", "lump in breast", "nipple rashes", "skin changes", "lump in the axilla", and "sudden change in size of the breast". The responses were recorded as "yes", "no", and "don't know".

Variables associated with help seeking are "Embarrassment", "Fear about cancer", "Wasting doctors time", "Difficulty in talking to the doctor about symptoms", "Difficult to get appointment with the doctor", "Too busy to make time to go to the doctor", "Too many other things to worry about", "Difficult to arrange transport to doctors clinic", "Worrying about what the doctor might find", "Not feeling confident talking about my symptoms with the doctor", and time taken to consult first healthcare worker. There was also an open-ended question which asked about "Any other reasons which they could think about".

3.6.7: Data Analysis

Data collection forms were scrutinized for any incomplete or missing columns or inappropriate responses and subsequently were entered in appropriate statistical software program. The unique identification code given was the same as that in the registry data of the patient. Variables were coded appropriately. Recoding was done wherever needed. After data cleaning, analysis of data was done by using a statistical software with tools for data management and analysis. Frequencies and proportions were used to describe categorical variables. Mean and standard deviations were calculated for continuous variables. Bivariate analysis of categoric variables was performed with the help of contingency tables and Chi square statistics or Fischer's exact test. Significant alpha level was taken as 0.05 for Chi-square and Fisher's exact tests. Univariate logistic regression was performed with categoric intervals of the dependent variable for calculating unadjusted OR and 95% confidence interval. Regression analysis was done finally for a predictive model for work ability and depression among survivors.

3.6.7.1: Background characteristics of study participants

3.6.7.1.1: Univariate analysis: Age was described in terms of means and standard deviation. Frequencies and proportions were done for sociodemographic variables like education, marital status, parity and occupation. Regarding disease, type of surgery, stage of disease of disease, present stage, comorbidities, vital status, whether taking treatment now, long term and late effects of treatment were also described as frequencies or proportions.

Self-assessed work ability scores were described as frequencies and proportions after categorising into 'Poor', 'Moderate', 'Good' and 'Excellent'

Scores of depression level (PHQ 9) and anxiety levels (GAD 7) among survivors was also described as frequencies and proportions after categorising into 'none', 'mild', 'moderate' and 'severe'.

Present awareness regarding risk factors of breast cancer among survivors were described in terms of frequencies and proportions (categorised into agree, not sure and disagree). Awareness regarding symptoms of breast cancer were further categorised into ‘yes’ and ‘don’t know’.

Reasons for barriers in help seeking behaviour were also described as frequencies.

3.6.7.1.2: Bivariate analysis

Relevant variables which are likely to exhibit possible interactions were selected to find out empirical associations between those variables. For this purpose, cross tabulations and Chi square test of independence were done between sociodemographic factors and disease factors. Wherever the contingency table contained a count less than five, the Fischer’s exact test was done.

3.6.7.1.3: Work ability and associated factors

To find out the decisive variables associated with work ability, a bivariate analysis of the various sociodemographic variables, long term health effects of treatment which were experienced at present like fatigue, pain, mood changes, treatment induced menopause, presence of comorbidity, present disease status, type of surgery, present level of anxiety, and present level of depression were done. For this the score of Work Ability Index was dichotomised to “Poor to Moderate” and “Good to Excellent”. This was done on the basis of the mean WAI score of the study. Values above this score were included in Good to Excellent and values below this to “Poor to Moderate”. The variables which were significantly associated (p value <0.05) were selected for multivariate analysis.

Binary logistic regression was performed with the dichotomised work ability scores as dependent variable and other variables as covariates. Thus, the most predictive model for work ability of survivors was formulated by purposeful selection of covariates with significant associations and through a process of model refitting and verifications multiple times till the perfect fit was obtained.

3.6.7.1.4: Depression and associated factors

To find out the variables which were significantly associated with one of the most frequent psychosocial problems among survivors, the steps for bivariate analysis which were described above were followed. For this purpose, the present depression level scores (PHQ 9 scores) were dichotomised to “No depression” and “depression”. Those variables which showed a significant association with p value less than .05 after cross tabulation and Chi square /Fischer Exact test were selected for further analysis.

Following this binary logistic regression was performed to find out the predictive variables. Here, the dichotomised depression scores were taken as the dependent variable and other variables as covariates. The final model with significant predictors was obtained.

3.6.7.1.5: Anxiety and associated factors

Present anxiety scores were categorised into “no anxiety” and ‘anxiety” based on the score cut off points as mentioned in the methodology section. Bivariate analysis was performed to find out variables which were significantly associated with anxiety levels in survivors. The same set of variables were used.

A binary logistic regression analysis was also tried with the selected variables. But since, a satisfactory predictive model could not be obtained, the attempt was abandoned.

3.6.7.1.6: Awareness about symptoms and risk factors of breast cancer

3.6.7.1.6.1: Present level of awareness about risk factors among survivors

The variables regarding risk factors of breast cancer were described in terms of frequencies and proportions and were represented in a graphical manner. The open-ended question regarding “any other risk factor which you could think of” was described as frequencies and also represented graphically.

3.6.7.1.6.2: Present level of awareness about symptoms among survivors

The variables related to symptoms of breast cancer was described as frequencies and proportions. They were also graphically represented.

3.6.7.1.7.: Barriers in the initial help seeking process

The variables in the questionnaire on help seeking barriers in the initial diagnosis were described as frequencies and proportions and represented in a graphical manner.

The open-ended question as to “can you think of any barriers other than this which might have interfered with your help seeking?” was also analysed and categorised to themes to further throw light upon this issue.

3.7: Phase 2: In depth interviews with survivors who were disease free and with survivors who are having recurrence of disease (qualitative component)

3.7.1: Study type

The in-depth interviews consisted of the qualitative part of the study. The findings from the in-depth interviews were used to have a better understanding of the survivorship experiences and to substantiate the quantitative findings. The interviews were conducted by using the interview schedule. The preparation of the interview schedule has been detailed in Section 3.4.3. Interviews were conducted among survivors who are presently free of disease and those who are presently having disease recurrence and on treatment.

3.7.2: Sample size

In depth interviews were conducted among fifteen survivors who are presently free of disease and ten survivors who are having disease recurrence at present. The sample size was based on the principle of saturation. Data collection was stopped on attainment of saturation.

3.7.3: Sample selection procedure

Participants were conveniently selected from those included in the follow up survey. Those who had time and were willing for the interview were included. Among those who were having disease, all ten were included. The interviews were conducted during their follow up visits in the hospital or at any place convenient to them. Care was taken to include a variety of participants, so that different perspectives of survivorship could be captured. A total of 25 in depth interviews were conducted.

3.7.4: Data collection procedure

The in-depth interview checklist was separate for survivors who were disease free and those with disease at present. Interview checklists were initially prepared in English. A conceptually equivalent Malayalam version of the checklists was also prepared. The interviews were conducted mostly during the follow up visits of the survivors. It was conducted along with the quantitative part of the study. The participants were asked if they had time for the interview also. If they were willing, the consent for the interview was also taken. The interviews were conducted in the same room near the outpatient department as the follow up survey after ensuring privacy. The interviews were conducted among those who are presently disease free as well as those having disease at present.

Those who were disease free were asked about their perception of being a "survivor", whether they returned to their regular work and the challenges they faced, the support they received from the community, the stigma related to breast cancer which they experienced, the good and bad experiences during their survivorship, their perceptions about the additional facilities they need during their follow up care, and the financial support they received during their treatment. Survivors having disease recurrence or living with the disease at present were asked about their perceptions on disease recurrence, financial burden of treatment for the second time, how the crisis was managed by family, and the work-related challenges faced by them due to their ailments, and treatments.

3.7.5: Data analysis

Data analysis was done manually. The interviews in Malayalam were first transcribed into English. After transcribing, and correcting language, the English version was coded following axial coding. Codes were clustered into themes based on the patterns which emerged and then categorised.

3.8: Phase 3: Document review

A review of documents was done to understand the importance given to cancer control, especially breast cancer control in the state. We also wanted to understand the policy related to breast cancer survivorship in the documents if any.

The documents related to cancer control were collected, which included government documents, those published by oncology institutions and those available through online sources. The review of documents was done by utilising the prepared check list, which received approval from the IEC of both institutions. All health-related government portals and medical libraries of the three comprehensive cancer centres were searched manually for policy documents related to cancer. Discussion with experts who were involved in the preparation of policy related documents was also done. A systematic search for documents was also done in PubMed using the keywords which include "health policy", “cancer”, “breast cancer", "guiding documents", “survivorship”, “breast cancer survivorship”, and “Kerala" which did not yield any positive results. Various health related websites of Government of Kerala were also browsed. The websites included www.dhs.kerala.gov.in, www.dme.kerala.gov.in, www.kerala.gov.in, www.arogyakeralam.gov.in, www.rcctvm.gov.in, www.mcckerala.gov.in, and www.ccrc.kerala.gov.in.

After these steps, fifteen documents were identified, out of which four documents regarding detailed cancer control policy were reviewed for analysis. Documents which did not mention either cancer control or breast cancer control/early detection or survivorship were excluded. They include Kerala Old age policy 2006, State old age policy 2013, Pain and palliative care policy 2008, Kerala state policy on palliative care 2019, Women’s policy 2009, Draft Kerala labour policy 2011, Youth policy 2012, Kerala state labour policy 2017, Kerala sports policy 2012, and State policy for persons with disabilities 2014. The draft health policy 2018 was same as Health policy 2019, hence excluded.

The following documents were finally included in the review:

1) Ten-year action plan for cancer control in Kerala 1988 (Nair Krishnan M, 1988).
2) Draft Kerala Health Policy 2013(Health Policy Kerala, 2013)
3) Kerala Cancer Control Strategy 2018-2030 (Kerala cancer control strategy, 2018).
4) Kerala Health policy 2019(Health policy Kerala, 2019).

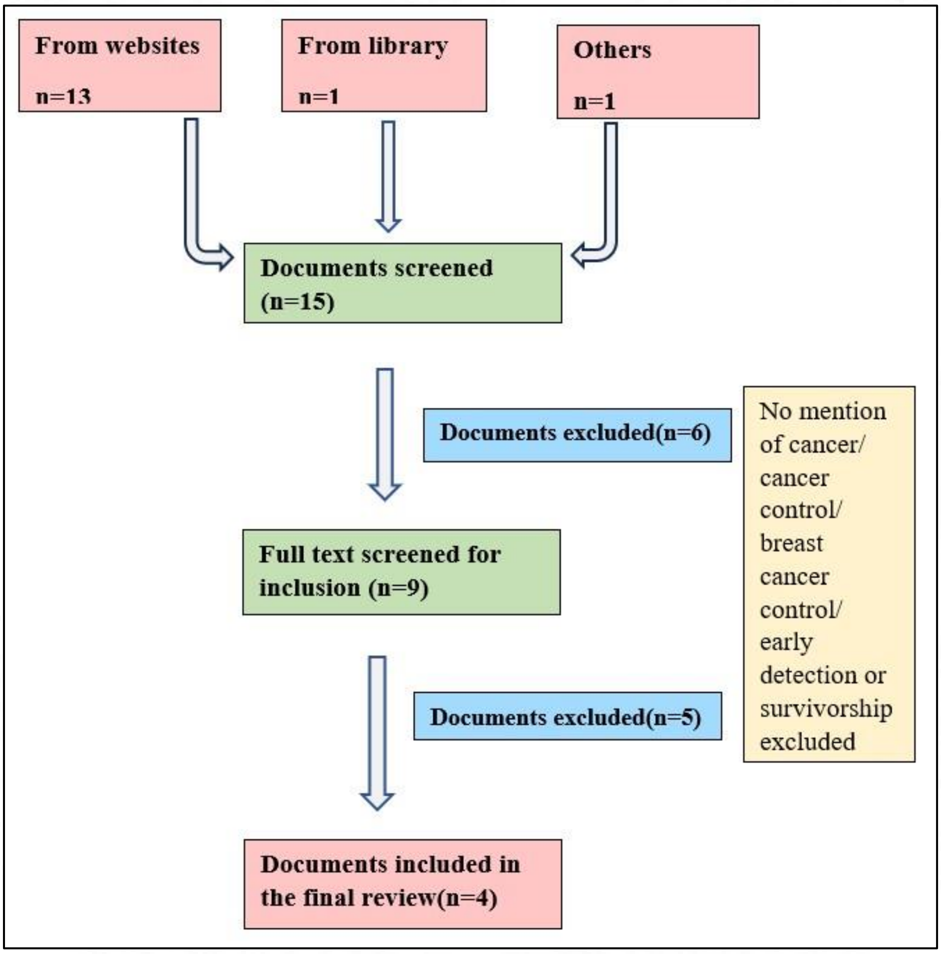


Figure 3.4: Document review selection process

Fig 3.4 shows the selection process of the documents for policy analysis. The documents included in the review were analysed using the document review checklist to identify the key institutions and organizations involved in cancer/breast cancer prevention in the State. The document was also assessed for identifying initiatives and measures taken for early breast cancer diagnosis as well as the proposed strategies and plans for breast cancer follow-up and survivorship plans

3.9: Ethical considerations

3.9.1: Permissions and approval

The Ethical clearance for the study was obtained from the Institutional Ethics Committee, Sree Chitra Tirunal Institute for Medical Science and Technology, Trivandrum and Institutional Ethics committee, Malabar Cancer Centre, Thalassery where the study was conducted (1617/IRB-IEC/13/MCC/26-05-2021/2 and SCT/IEC/1711/AUGUST/2021).

3.9.2: Respect for persons

3.9.2.1: Autonomy: Only those patients who voluntarily consent for the study will be included. They will be advised about the voluntary nature of participation and their right to withdraw from the study whenever they feel so.

3.9.2.2: Informed consent: The participant information sheet and informed consent form are prepared in lay language to make sure that each participant thoroughly comprehends the nature of the study and what is expected from them during the study.

3.9.3: Beneficence

3.9.3.1: Benefits: By participating in this study, patients themselves will not receive any specific benefits but their contribution by participating in the study will benefit the society.

3.9.3.2: Harms: The timing and place of the data collection will be as per convenience of the woman. Scheduling of data collection on a follow up may also be considered if it is convenient to them.

3.9.4: Justice

3.9.4.1: Involvement of vulnerable population: Study is not directed at any particular vulnerable population. No harms are involved in the study.

3.9.4.2: Privacy and confidentiality: The researcher will ensure the confidentiality of participants and data security by undertaking certain measures as given below.

1. The contact details of the supervisor and IEC Secretary will be given in the participant information sheet. Each participant can contact any of them for further clarifications, if needed.

2. Data will be collected at place and time convenient for the participants.

3. The researcher only will be in the room or space during the interview.

4. The personal information will be masked by giving identification number to each data sheet.

5. The researcher will remove face sheets containing identifiers from survey instruments after the data entry.

6. Data will not be shared with anyone, other than the supervisor.

7. Data will be kept safely in a locked cupboard.

8. Security codes will be assigned to computerized records

RESULTS

Chapter 4

Results

The results chapter is organized into three major sections; **Section 1** deals with results based on HBCR-based data, **Section 2** deals with the results of the follow-up survey (both quantitative and qualitative), and **Section 3** deals with results of document review.

4.1. Section 1: Findings based on Hospital-Based Cancer Registry Data

4.1.1. Profile of study participants included in HBCR in the year 2016

4.1.1. Sociodemographic profile

The total number of female breast cancer patients registered in the TCC in 2016 as per HBCR was 534.

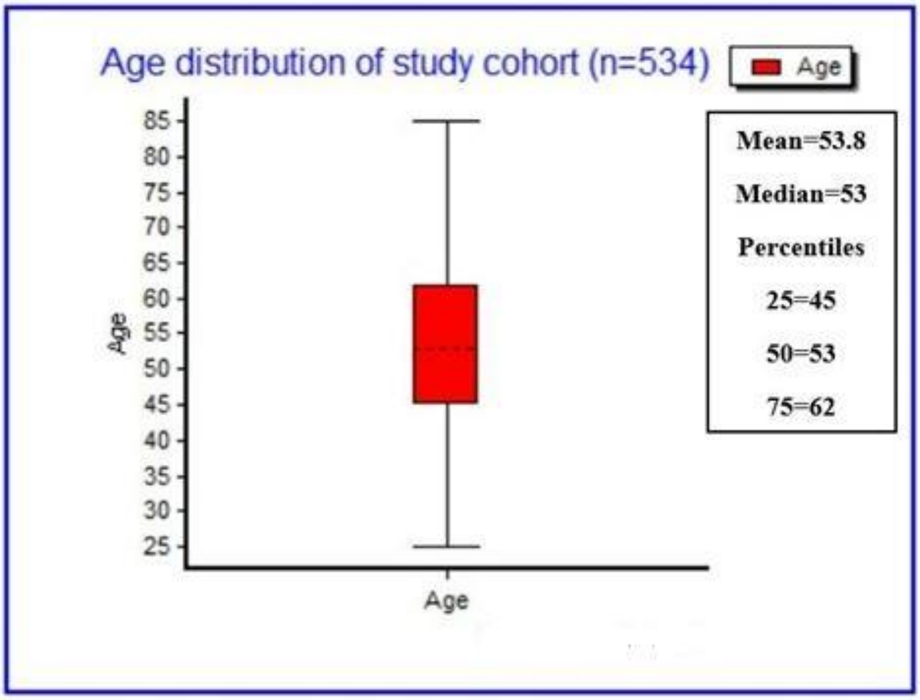
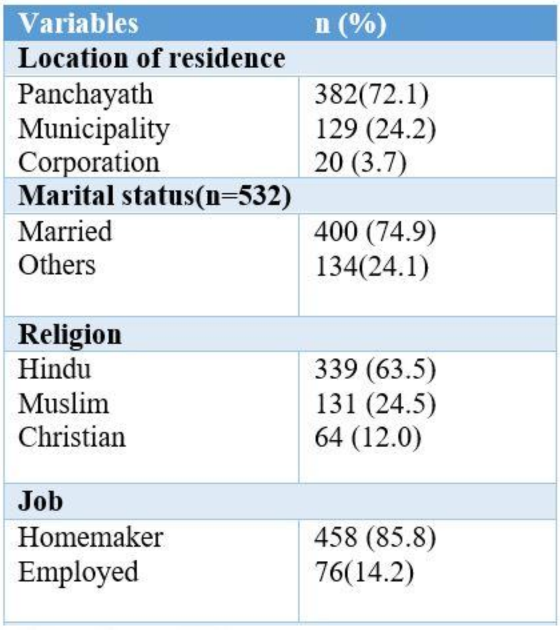


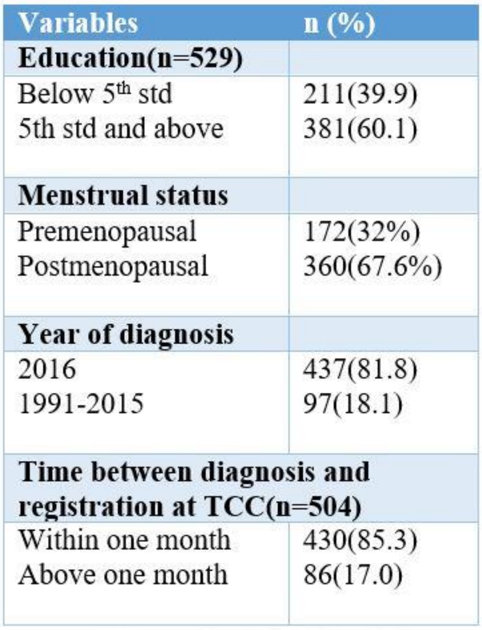
Figure 4.1: Box plot describing the age of the study participants (n=534)

The mean age was 53.8 (SD±12.1), the range being 25 years to 85 years of age (both included). The 95% confidence interval for the mean was 52.77 -54.83. The standard error of the mean is 0.52. The median age (IQR) was 53 years (45 -62). Age distribution followed a normal distribution pattern. Two-fifths of the participants (n=211) were less than 50 years of age and the remaining (n=323) were 50 years and above. More than half of the participants were between 45 and 54 years of age. The majority of the study participants were females (99.6%).

Table 4.1: Sociodemographic profile of the study participants (n=534)



Variables	n (%)
Location of residence	
Panchayath	382(72.1)
Municipality	129 (24.2)
Corporation	20 (3.7)
Marital status(n=532)	
Married	400 (74.9)
Others	134(24.1)
Religion	
Hindu	339 (63.5)
Muslim	131 (24.5)
Christian	64 (12.0)
Job	
Homemaker	458 (85.8)
Employed	76(14.2)



Variables	n (%)
Education(n=529)	
Below 5th std	211(39.9)
5th std and above	381(60.1)
Menstrual status	
Premenopausal	172(32%)
Postmenopausal	360(67.6%)
Year of diagnosis	
2016	437(81.8)
1991-2015	97(18.1)
Time between diagnosis and registration at TCC(n=504)	
Within one month	430(85.3)
Above one month	86(17.0)

The total number of female breast cancer patients registered in the TCC in 2016 as per HBCR was 534. The majority of the study participants were Hindus (63.5%), followed by Muslims (24.5%) and Christians (12%). As per the location of their houses, 71.5% lived in the panchayath area,24.2% in the municipality area, and 3.7% in the corporation area. For analysis, panchayaths have been described as rural areas, and municipality and corporation areas have been grouped as urban areas. More than half of the participants were from the district of Kannur, followed by Kasargode district (16.3%), Kozhikode district (15.2%), and the remaining in varying numbers from Districts of Wayanad, Palakkad, and Malappuram. Four of them were from the neighbouring state of Karnataka and five were from Mahe, a part of the Union Territory of Puducherry. (Fig 4.2).

Figure 4.2: Map of Kerala with the district of residence of study participants marked in red

Three fourth of the women were married. The “others” category included not only unmarried women (6.6%), but also those who were either widows, divorced, or separated (18.1%). Malayalam was the mother tongue of 99% and a few were Kannada-speaking.

In the education category, 60.5% had passed the fifth standard and 39.5% had below the 5th standard education. The 'below fifth standard' comprised those with no formal education (19.8%) or some form of education (19.5%) such as primary education. The 'above 5th standard' is comprised of those who have passed the fifth standard (middle school) and attained education above that. Only 12% had a university degree.

Homemakers constituted 85.8%. Among those who were employed, 7.3% were manual labourers and 6.9% were teachers or doing clerical jobs and 3.6% were professionals.

The HBCR of the year 2016 is a record of all cancer patients who got themselves registered in the TCC during the whole year. It has separate sections for each cancer.

The breast section gives a record of all the breast cancer patients who registered at the TCC during the entire year (January to December), irrespective of their year of diagnosis. Here, we are considering only female breast cancer patients. HBCR consisted of patients newly diagnosed in 2016(81.8%), and those diagnosed between 1991 and 2015(18%), also registered in the TCC for the first time in 2016.

The majority who registered in 2016 reported to the TCC within one month of diagnosis (85.3%). Of these, half of the patients (49.6%) registered themselves in the TCC within one week of diagnosis, and the rest between 8 days and one month of diagnosis (30.8%). The date of diagnosis is taken as the date on the laboratory reports of cytology or biopsy samples. The registration date is the date when the patient first came to TCC and registered for treatment.

4.1.1.2: Disease profile

Table 4.2: Description of the disease profile of the study participants (n=534)

Variables	**n (%)**
Morphology	
Invasive duct ca-ET	461 (86.3)
Lobular ca-ET	8 (1.5)
Papillary ca-ET	6 (1.1)
Carcinoma NOS	14 (2.6)
Phyllodes tumour	3 (0.6)
Mucinous ca	9 (1.7)
Medullary ca	2 (0.4)
DCIS	5 (0.9)
Others	8(1.5)
Unknown	18(3.4)
HER2 status	
Positive	248(46.4)
Negative	173 (32.4)
Equivocal	7(1.3)
Unknown	106(19.9)
Ki67 status	
0-2% grade 1	11(2.1)
2-20% grade 2	104 (19.5)
>20% grade 3	156 (29.2)
Inconclusive	34 (6.4)
unknown	229(42.9)
Diagnostic status at registration	
Microscopically confirmed	448(83.9)
Suspected radiologically/ Microscopically	54(10.1)
Clinically/to r/o malignancy	32(6.0)
Time between registration and treatment start at TCC (n=396)	
Within 1 month	292(54.6)
Between 1 and 2 months	87(16.3)
>2 months	17(3.1)
Treatment status	
Treatment completed	330(61.8)
Treatment not taken/incomplete treatment	204(38.2)
Disease status at 6 months	
No disease	312(58.4)
others	222(41.5)

About 83.9% had a microscopic confirmation at diagnosis, histology of primary being the most frequent. Invasive duct carcinoma was the histological report of 86.3% of patients. The Estrogen Progesterone receptor (ER PR) status of the study participants is given below:

Table 4.3: ER PR status of the samples of study participants (n=443)

	PR positive n (%)	**PR negative** n (%)
ER-positive n (%)	234(43.8)	42 (7.9)
ER-negative n (%)	5(0.9)	162 (30.3)

In the majority of the patients, the breast was the primary site of malignancy. Twenty-three participants reported having more than one primary. Looking into the time between registration and treatment starting in TCC, it was found that nearly 50% started their treatment between 8 days and one month of registration, and 16.3% started their treatment between 30 to 60 days. Those who took treatment from TCC and completed it were 61.8%, the rest, either did not take any treatment (24.5%) or took only incomplete treatment (13.7%). Among the participants, 58.5% were disease free at six months. The 'others' included those with residual disease (2.4%), with disease progression or recurrence (8.2%), with second malignancy (n=3,0.6%), and those who succumbed to the disease at six months (4.9%). In 25.5% the disease status at six months was unknown (They either did not report back to the TCC, did not take treatment from TCC, or came only for a second opinion).

4.1.1.3: Stage at registration

Figure 4.3 gives a picture of the stage of disease of the participants at the time of registration in the TCC. The graph represents stages of breast cancer while the participant registered in the TCC. The majority of the participants were in stage 2 (54.1%) during their registration at TCC, and the remaining 45.8%were in stage 1, stage 3, and, stage 4.

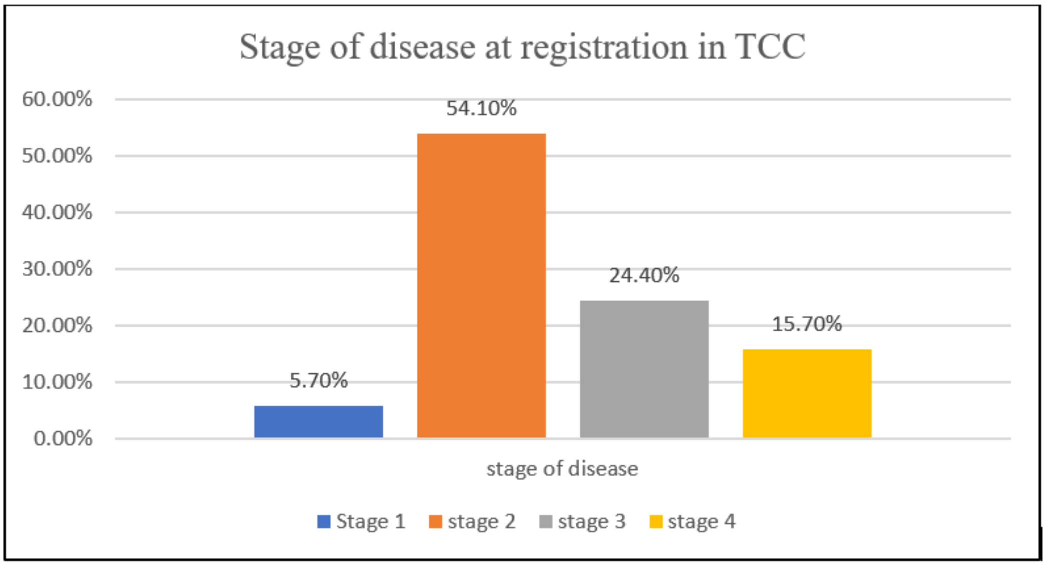


Figure 4.3: Stage of disease of study participants at registration in TCC(n=528)

For further analysis, the stages were grouped into ‘early stage’ (stages 1 and 2) and ‘late stages’ (stages 3 and 4). We further wanted to analyse the factors associated with the stage of disease, the factors associated with the time between diagnosis and registration at the TCC, and the factors associated with the nontreatment/ partial treatment of the study participants. For this analysis, we considered only the participants who were newly diagnosed in 2016 and included in the HBCR. (n=437).

4.1.2: Factors associated with stage of disease, the time between diagnosis and registration at TCC, and treatment status of study participants

The HBCR of 2016, not only consists of patients newly diagnosed in 2016, but also those diagnosed between 1991 and 2015. Analysing a heterogenous group may not be meaningful. Hence, for this analysis, we considered only the female breast cancer who were newly diagnosed in 2016 and included in the HBCR (n=437).

Table 4.4: Sociodemographic and disease profile of the study participants(n=437)

Variables	n (%)
Age at diagnosis	
<50 years	183(41.9)
≥50 years	254(58.1)
Location of residence	
Urban	125(28.6)
Rural	312(71.4)
Marital status	
Married	335(76.7)
Others	102(23.3)
Religion	
Hindu	288(65.9)
Muslim	98(22.4)
Christian	51(11.7)
Job	
Homemaker	368(84.2)
Employed	69(15.8)
Education	
Below 5^{th} std	176(40.3)
5th std and above	261(59.7)
Stage of disease at registration at TCC	
Early stage	286(65.4)
Late stage	151(34.6)
The time between diagnosis and registration at TCC	
Within one month	391(89.5)
Above one month	46(10.5)
Treatment status	
Treatment completed	299(68.4)
Treatment not taken/ incomplete	138(31.6)

The number of study participants diagnosed in 2016 and registered in the TCC during 2016 is 437. Table 4.4 describes the profile of the study participants.

The majority of women (58.1%) were of age 50 years and above. About 71.4% of the participants were residing in rural areas, and 28.6% were in urban areas. Married women constituted a majority (76.7%). Most women were homemakers, with employed women constituting only 15.8%. About 59.7% of women had an education above fifth standard, and 40.3% had an education below fifth standard.

Women diagnosed in the early stage were 65.4%, while 34.6% were diagnosed in the late stages. A majority (89.5%) of women reported to TCC within one month of getting a confirmed lab diagnosis, while 10.5% of women took more than one month. With regard to treatment status, 68.4% of those who took treatment from TCC completed their treatment, while 31.6% either did not take treatment or took only partial treatment.

4.1.2.1: Factors associated with the stage of disease presentation

We performed bivariate analysis to find any association between sociodemographic factors and disease factors with stages of disease presentation. The table below shows the factors associated with the stage at which the patients initially presented at TCC.

Table 4.5: Factors associated with stage of disease at registration(n-437)

Variables	**Stage of disease**		**Chi-square**
	Early-stage	**Late stage**	**p-value**
Education			
Below 5th std	105(59.7)	71(40.3)	0.04*
5th std and above	181(69.3)	80(30.7)	
Location of residence			
Urban	82 (65.6)	43(35.4)	0.98
Rural	204(65.4)	108(34.6)	

Table 4.5 ctd…

Marital status			
Married	217(65.8)	118(35.2)	0.59
Others	69(67.6)	33(32.4)	
Age at diagnosis			
<50 years	128(69.9)	55(30.1)	0.09
≥50 years	158(62.2)	96(37.8)	
Religion			
Hindu	193(67.0)	95(33.0)	0.32
Muslim	58(59.2)	40(40.8)	
Christian	35(68.6)	16(31.4)	
Job			
Homemakers	241(65.5)	127(34.5)	0.96
Employed	45(65.2)	24(34.8)	
The time between diagnosis and registration at TCC			
Within one month	256(65.5)	135(34.5)	0.97
Above one month	30(65.2)	16(34.8)	

*p-value significant at $p<0.05$

This table demonstrates the factors associated with the stage of disease when the patient registered in the TCC. It was found that among the factors studied, educational status was associated with the stage at presentation and was found to be statistically significant. Those who had education above the fifth standard (69.3%) presented in the early stages.

Among those who were less than 50 years of age, about 70 percent presented in the early stage as opposed to those who were more than 50 years of age (62%). However, a statistically significant association could not be demonstrated. Other factors like place of residence, marital status, religion and occupation, and the time interval between disease diagnosis and registration did not find any significant association.

4.1.2.2: Factors associated with time between diagnosis and registration at TCC

Bivariate analysis was done to find any association between sociodemographic factors and other disease factors and the time between diagnosis and presentation at TCC (n=437)

Table 4.5 given below shows the factors associated with the time between diagnosis and presentation at TCC. Here the date of diagnosis is taken as the date of reporting of cytology or biopsy samples as given in the laboratory reports and available in hospital records of the patient. The date of registration is the date when the patient first came to TCC and registered for treatment.

Table 4.6: Factors associated with the time between diagnosis and registration at TCC (n=437)

Variables	Within 1 month	Above one month	Chi-square p-value
Education			
Below 5th std	162(92.0)	14(8.0)	0.15
5th std and above	229(87.7)	32(12.3)	
Place of residence			
Urban	115 (92.0)	10(8.0)	0.27
Rural	276(88.5)	108(34.6)	
Marital status			
Married	295(88.1)	40(11.9)	0.09
Others	96(94.1)	6(5.9)	
Age at registration			
<50 years	161(88.0)	22(12.0)	0.38
≥50years	230(90.6)	24(9.4)	
Stage of disease			
Early stage	256(89.5)	30(10.5)	0.97
Late stage	135(89.4)	16(10.6)	
Religion			
Hindu	264(91.7)	24(8.3)	0.08
Muslim	85(86.7)	13(13.3)	
Christian	42(82.4)	9(17.6)	
Occupation			
Homemaker	330(89.7)	38(10.3)	0.75
Employed	61(88.4)	8(11.6)	

It was found that the majority presented at the TCC within one month of diagnosis (after obtaining a lab report confirming a diagnosis). No significant association could be found between this time interval and factors like education, place of residence, marital status, age at registration, religion, or occupation.

4.1.2.3: Factors associated with treatment status of study participants (n=437)

Among those who were newly diagnosed in 2016, 68.4% completed treatment from TCC while 31.6% either took partial treatment or did not take any treatment. Bivariate analysis was done to find any association between sociodemographic and other factors and the status of treatment taken from TCC. Complete treatment refers to those who have completed their prescribed treatment of surgery/ chemotherapy/ radiotherapy and are on /not on hormone therapy. If women either declined or took only part of the prescribed treatment they were included in the 'no/partial treatment' group.

Table 4.7: Factors associated with the treatment status (n=437)

Variable	Complete treatment	No/Incomplete treatment	Chi-square p-value
Education status			
Below 5th std	117(66.5)	59(33.5)	0.47
5th std and above	182(69.7)	79(30.3)	
Place of residence			
Urban	79(63.2)	46(36.8)	0.13
Rural	220(70.5)	92(29.5)	
Marital status			
Married	231(69.0)	104(31.0)	0.66
Others	68(66.7)	34(33.3)	
Age at diagnosis			
<50 years	127(69.4)	56(30.6)	0.70
≥50years	172(67.0)	82(32.3)	
Religion			
Hindu	205(71.2)	83(28.8)	0.21
Muslim	61(62.2)	37(37.8)	
Christian	33(64.7)	18(35.3)	

Table 4.7 ctd.			
Occupation			
Homemaker	247(67.1)	121(32.9)	0.17
Employed	52(75.4)	17(24.6)	
Stage at diagnosis			
Early stage	206(72.0)	80(28.0)	0.02*
Late stage	93(61.6)	58(38.4)	

*p-value significant at $p<0.05$

It was found that the treatment status was associated with the stage at diagnosis and was statistically significant. Complete treatment was taken by 72% of those diagnosed in the early stages, whereas 38.4% of women diagnosed at the late stages either did not take treatment or took incomplete treatment. It was also noted that 75.4% of women who were employed took complete treatment, while 32.9% of homemakers took either incomplete or no treatment. However, this association was not statistically significant.

Also, it is of interest to note that 70.5% of those residing in rural areas have taken complete treatment, while 36.8% of those dwelling in urban areas either took incomplete or did not take any treatment from TCC.

4.2: Section 2: Findings of the follow-up survey conducted among survivors in 2022 (n=209)

A follow-up survey was conducted among the study participants after six years, in 2022. Section 2 of the results chapter describes the results of the quantitative and qualitative part of the study among survivors (n=209).

4.2.1: Profile of survivors during the follow up survey in 2022 (n=209)

The number of survivors who were included in the follow-up survey was 209. The sample size and sample selection are described in detail in the methodology section. The sociodemographic profile of the study participants in the follow-up survey is presented in Table 4.8 given below.

Table 4.8: Sociodemographic profile of study participants(n=209)

Variables	n (%)
Present age	
<50 years	66(31.6)
≥50 years	143(68.4)
Parity	
No children	12(5.9)
Have children	190(94.1)
Present marital status	
Married	166(79.4)
Others	43(20.6)
Stage at diagnosis	
Early stage	160(76.6)
Late stage	49(23.4)
Type of surgery done	
MRM	156(74.6)
BCS	53(25.4)
Present disease status	
No disease	199(95.2)
Having disease	10(4.8)
Present job status	
Homemaker	170(81.3)
Employed	39(18.7)
Education	
Below 5th standard	34(16.3)
5th standard and above	175(83.7)

The number of study participants who registered in TCC in 2016 is 534. The changes in the cohort from 2016 to 2022 are given in Fig 3.3, methodology section **3.6.1.** The present analysis is done on survivors who were traceable in 2022 and consented to take part in the study. There were 209 survivors who were under follow-up and consented to take part in the study.

Looking into the profile of survivors. it is found that 31.6% of survivors were less than 50 years of age presently, and 68.4% were either 50 years and above. Women who were having the educational status of fifth standard and above were 83.7%, while 16.3% had education below fifth standard. A majority (94.1%) were having children, and only 5.9% of survivors had no children. Married women included 79.4%, while 20.6% were either unmarried, widowed, or staying separated from their spouses. The stage of diagnosis was either stage 1 or 2(early stage) in 76.6% and 23.4% were in stage 3 or 4 (late stage). As part of their treatment, 74.6% of women underwent mastectomy or removal of the entire breast (MRM) and 25.4% underwent breast-conserving surgery (BCS). Employed women constituted 18.7% and the rest were homemakers (81.3%). The number of study participants who are presently disease free included 95.2% and ten women (4.8%) progressed to stage 4 and are currently living with the disease and on treatment. When compared with 2016, nine women were widowed and one got divorced, seven women lost their job, while two started doing new jobs, and ten women progressed to stage 4 disease.

The following chapter describes the results of the follow-up survey conducted among survivors. All these studies are conducted among 209 survivors who were traceable and under follow-up in 2022. The results are described below.

4.2.1.1: Long-term and late physical effects of treatment among the study participants (n=209)

Many treatment-related complications remain even after several years of treatment. Some of these health effects include pain, fatigue, edema of the arm (lymphoedema), numbness in arms and legs, chemotherapy-induced menopause, cognition-related issues, and mood changes.

The following bar chart (Figure4.4) gives the frequency of long-term health effects due to cancer treatment in our study subjects. (n=209)

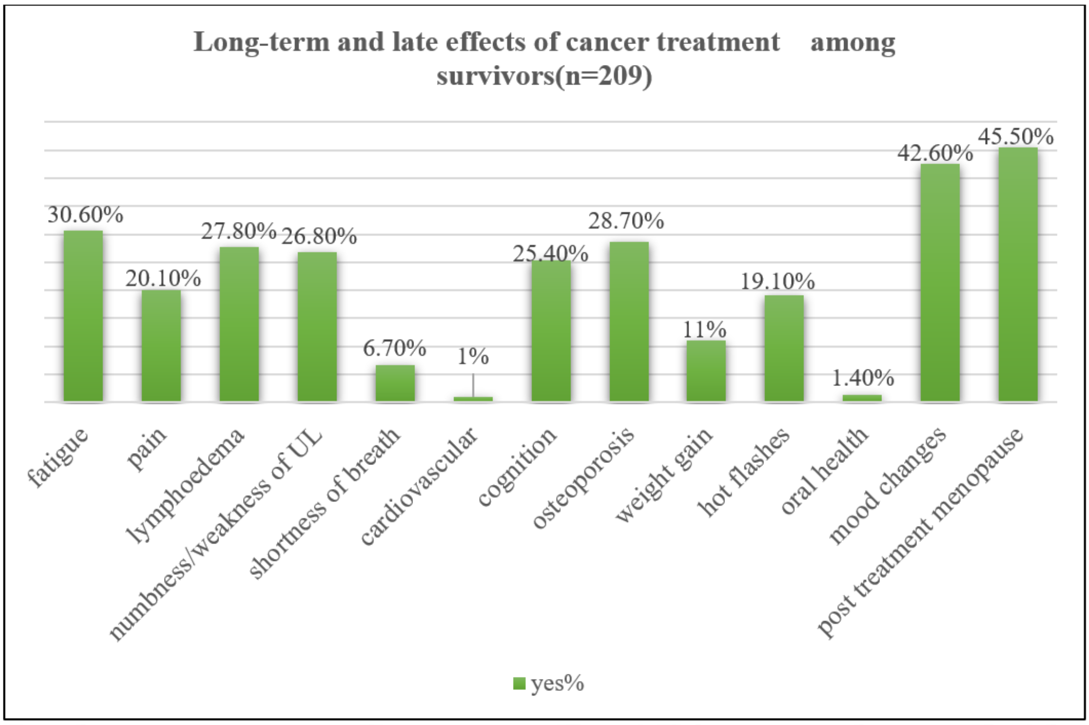


Figure 4.4: Bar chart showing long-term and late effects of cancer treatment among survivors (n=209)

Among the long-term side effects seen, fatigue (30.6%), lymphoedema (27.8%), numbness of arms (26.8%), cognition issues (25.4%), hot flashes (19.1%), mood changes (42.6%), and treatment-induced early menopause (45.5%) were most commonly seen. Though 28.7% of women described symptoms related to osteoporosis (either self-assessed or told to them by a doctor), only 50% of them were proven by investigations. Chemotherapy-induced early menopause and symptoms associated with it such as mood changes and hot flashes were described most commonly. Cardiovascular side effects (1%) and oral health issues (1.4%) were the least. It is to be noted that symptoms were reported by more than 25% of the survivors.

4.2.1.2 Work ability

4.2.1.2a: Self-assessed work ability among the study participants assessed using the Work Ability Index (WAI) (n=209)

The work ability of the study participants based on the WAI score is shown below (Fig 4.5). The mean work ability score of the study participants was 40.7 (95% CI 39.92 to 41.48), SD of ±5.73. The median is 43(range 19 to 47). For evaluation purposes, it is further categorized into 'suboptimal' (poor/moderate score 7-36) and 'optimal'(good/excellent score 37-49) (Ho et al., 2018). About 82% of the survivors have optimal perceived work ability and 18% have sub optimal work ability.

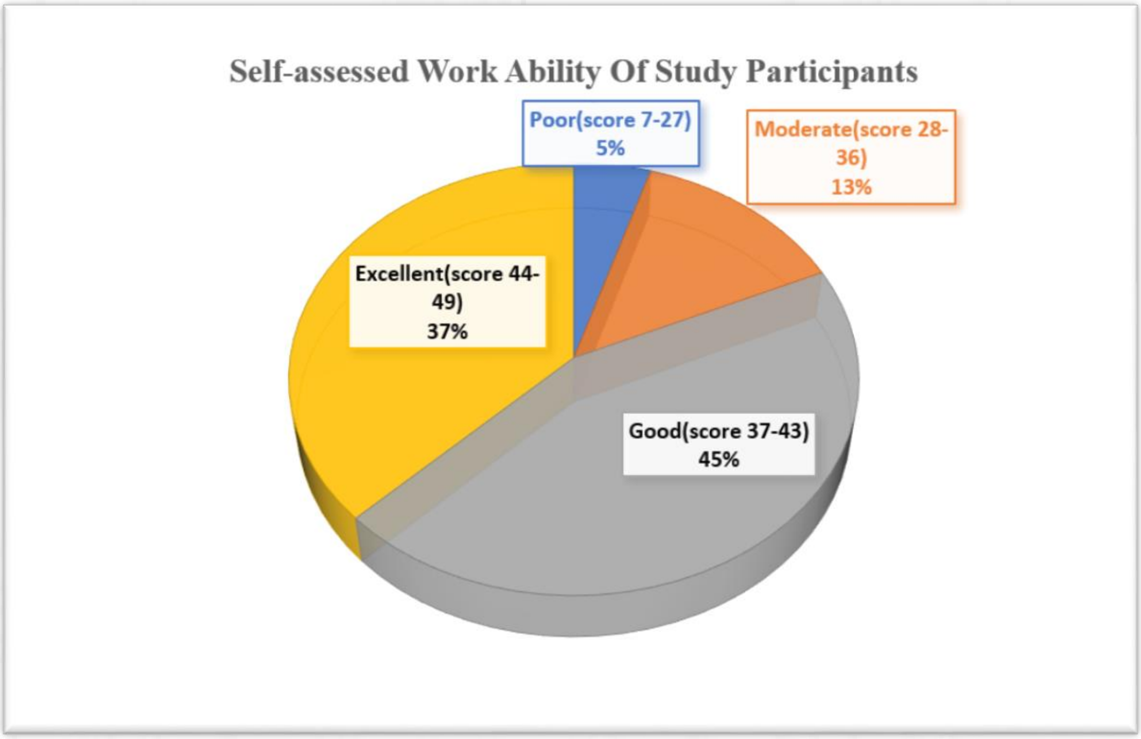
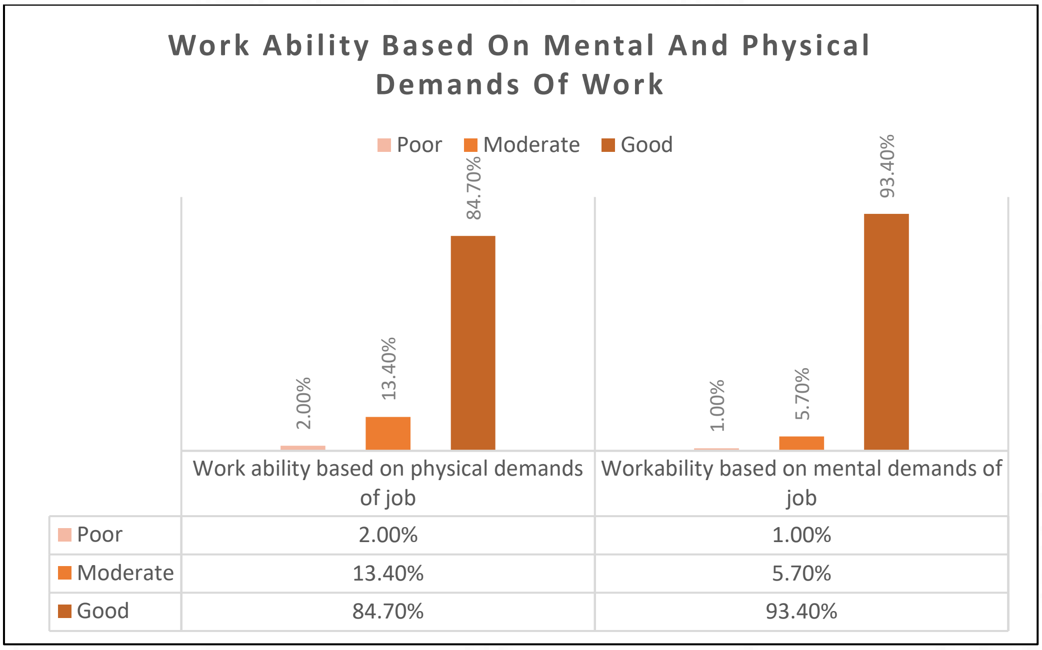


Figure 4.5: Self assessed work ability among survivors(n=209)

4.2.1.2b: The current work ability of the survivors when compared to lifetime best

When asked to report their present work ability on a scale from 0 to 10 (0 means cannot work and 10 denotes maximum work ability), 81.3% reported current work ability to be above 8 points. (Mean 8.49 ±1.45) and 95% CI of 8.29 to 8.69.

4.2.1.2c: The current work ability of the survivors based on the mental and physical demands of the work



	Work ability based on physical demands of job	Workability based on mental demands of job
Poor	2.00%	1.00%
Moderate	13.40%	5.70%
Good	84.70%	93.40%

Figure 4.6: Bar chart showing work ability of survivors based on physical and mental demands of the work (n=209)

In Figure 4.6, the graph describes the responses reported by the survivors when asked about their current work ability based on the physical and mental demands of their work. The responses were to be marked as ‘good’. ‘moderate’ or ‘poor’. About 84.7% reported they had good work ability regarding physical demands of the work and 93.4% of survivors reported that they have good work ability when compared with the mental demands of their work.

4.2.1.2.d: The estimated work impairment due to the disease

The following graph (Figure 4.7) describes the work impairment that the survivors had due to their disease condition (breast cancer). The following were the answers recorded when asked “whether your present disease condition was a hindrance to the work you are doing”. (More than one answer was possible)

Table 4.9: The estimated work impairment due to the disease (n=209)

Variables	Frequency (%)
There is no hindrance/I have no disease	38(18.2%)
Unable to do work as it causes some symptoms	91(43.5%)
Have to slow down or change work methods	90(43.1%)
I feel I can do only part-time work	6(2.9%)
Entirely unable to do work	2(1.0%)

Only 18.2% felt that they do not have any difficulty in doing their work. Difficulty in carrying out their work due to some symptoms was reported by 43.5% of women. Another 43% had to either slow down their work due to the disease or change their routine methods of doing the work. Only 2 women reported that they are entirely unable to work.

4.2.1.2.e: Own prognosis of work ability two years from now

The survivors were asked whether they felt that they will be able to continue with what they are doing now, even after two years.

About 5.3% reported that they were unlikely to do any work two years from now. About 21.1% were not sure whether they would be able to do any activities. About 74% were relatively sure that they will be able to continue with the activities they are doing now even after two years. 68.9% reported as enjoying their daily activities. When asked about their thoughts whether they will be able to work in the same manner two years from now 21 reported that they were not sure of it , while 74% reported that they were certain that they can continue work in the same manner.

4.2.1.2.f: Bivariate analysis to find any association between sociodemographic and other factors and the work ability of survivors.

Table 4.10 demonstrates the self-assessed work ability and associated factors (n=209). For the present evaluation, work ability is further categorized into 'Sub optimal' (poor/ moderate score 7-36), and 'Optimal'(good/ excellent score 37-49).

Table 4.10: Self-assessed work ability and associated factors (n=209)

Variables	**Work ability**		**Chi-square p-value**
	Sub optimal n (%)	**Optimal** n (%)	
Education			
Below 5th standard	8(23.5)	26(76.5)	0.37
Above 5th standard	30(17.1)	145(82.9)	
Marital status			
Married	23(13.9)	143(86.1)	<0.001*
others	15(34.9)	28(65.1)	
Parity			
Have children	32(16.8)	158(83.2)	0.23
No children	4(33.3)	8(66.7)	
Comorbidities			
Yes	11(19)	47(81)	0.85
No	27(17.9)	124(82.1)	
Stage at diagnosis			
Early	27(16.9)	133(83.1)	0.39
Late	11(22.4)	38(77.6)	
Type of surgery			
MRM	33(21.2)	123(78.8)	0.06
BCS	5(9.4)	48(90.6)	
Present age			
<50	7(10.6)	59(89.4)	0.05†
≥50	31(21.7)	112(78.3)	

Table ctd.

Present job			
Employed	1(2.6)	38(97.4)	0.003*†
Homemaker	37(21.8)	133(78.2)	
Fatigue			
yes	20(31.3)	44(68.8)	0.01*
No	18(12.4)	127(87.6)	
Pain			
Yes	15(35.7)	27(64.3)	0.001*
No	23(13.8)	144(86.2)	
Lymphoedema			
Yes	10(17.2)	48(82.8)	0.83
No	28(18.5)	123(81.5)	
Menstrual changes			
Post-treatment menopause	11(11.6)	84(88.4)	0.02*
No change	27(23.7)	87(76.3)	
Hot flashes			
Yes	5(12.5)	35(87.5)	0.36
No	33(19.5)	136(80.5)	
Osteoporosis			
Yes	14(23.3)	46(76.7)	0.22
No	24(16.1)	125(83.9)	
Mood changes			
Yes	18(20.2)	71(79.8)	0.50
No	20(16.7)	100(83.3)	
Present disease status			
Disease free	31(15.6)	168(84.4)	0.003*†
With disease	7(70)	3(30)	
Anxiety			
No anxiety	22(12.9)	148(87.1)	<0.001*
Anxiety	16(41.0)	23(59.0)	
Depression			
No Depression	24(12.7)	165(87.3)	<0.001*†
Depression	14(70.0)	6(30.0)	
Cognitive changes			
Yes	13(24.5)	40(75.5)	0.17
No	25(16.0)	131(84.0)	

*p-value significant at p<0.05 † Fischer’s exact test

It was found that sociodemographic factors like marital status, and job are significantly associated with work ability. Long-term effects of cancer treatment like fatigue, pain, chemo-induced menopause, present disease status, anxiety, and depression were other factors significantly associated with work ability among survivors.

Other factors like education, parity, stage of diagnosis, type of surgery, age, and other long-term effects of cancer treatment like lymphoedema, hot flashes, osteoporosis, mood changes, cognitive issues, and numbness or weakness of arms and legs did not have any significant association. Optimal work ability was seen in 90% of those who have undergone breast-conserving surgery (BCS), though a statistical significance was not obtained. Optimal work ability was also found in those below 50 years, though not found to be statistically significant.

4.2.1.2.g. Factors associated with work ability through binary logistic regression (n=209)

Binary logistic regression analysis was performed for determining possible predictors associated with work ability. The various assumptions to be satisfied before analysis was examined. The outcome (dependent) variable was dichotomous and predictor (independent) variables were categorical, observations were independent and categories were mutually exclusive.

The covariates for the model were selected purposively based on their statistically significant relations with work ability in the bivariate analysis. These variables were also found to be predictors of work ability through a literature review. Binary logistic regression was performed after the assumptions were found to be satisfactory. Going through the exercise of deleting covariates that were non-significant, refitting, and verifying, the final effect model was identified.

Logistic regression analysis was performed to see if education, marital status, occupation, fatigue, pain, menstrual changes, disease status, depression, and hot flashes were predictors of work ability among survivors. The dependent variable of interest was work ability among survivors of breast cancer, categorized into ‘Sub optimal ‘and ‘optimal’. The indicator showing the correct fitness of the model was that the Hosmer and Lemeshow test was not significant($\chi^2(7) = 6.613$, p=0.47). This means that the model adequately describes the data. The independent variables contributing to the model include “marital status”, “present disease status”, "occupation", "fatigue", "pain" and "depression", after controlling for "education"," chemo-induced menstrual changes" and hot flashes. Table 4.8 shows the logistic regression analysis of work ability and predictive factors.

Table 4.11: Summary of binary logistic regression analysis for variables predicting work ability among survivors (n=209)

Variables	Work ability Sub-optimal n (%)	 Optimal n(%)	Adjusted OR (95% CI)	Chi-square p-value
Marital status				
Married	23(13.9)	143(86.1)	7.15(2.61-19.55)	<0.005
Others	15(34.9)	28(65.1)	1	
Disease status				
Disease free	31(15.6)	168(84.4)	15.27(2.36-98.7)	.004
With disease	7(70.0)	3(30.0)	1	
Present job				
Employed	1(2.6)	38(97.4)	9.09(1.12-73.5)	0.04
Homemaker	37(21.8)	133(78.2)	1	
Depression				
No Depression	24(12.7)	165(87.3)	6.58(1.82-23.8)	0.004
Depression	14(70)	6(30)	1	
Fatigue				
Yes	20(31.3)	44(68.8)	1	
No	18(12.4)	127(87.6)	2.6((1.05-6.48)	0.040
Pain				
Yes	15(35.7)	27(64.3)	1	
No	23(13.8)	144(86.2)	3.11(1.16-8.35)	0.024

Note; Omnibus Tests of Model Coefficients χ^2 =58.2, df=9, p<.001 Likelihood ratio test: 139.969

Goodness-of-fit test: χ^2 =6.613, df=7, p=0.47 Nagelkerke R Square: 0.397

Overall percentage correct:85.6

The model predicts that being in a marital relationship (OR, 7.15; 95%CI 2.61 to 19.55) was associated with optimal work ability compared to those who were unmarried or divorced. Having a job (OR 9.09; 95%CI 1.12 to 73.5) was associated with optimal work ability compared to those who were homemakers. Being disease free at present (OR, 15.27; 95%CI 2.36 to 98.7) was associated with optimal work ability compared to those who had a recurrence of the disease. Having no depression (OR,6.58; 95%CI 1.82 to 23.8) when compared to those with mild, moderate, and severe depression was associated with optimal work ability as per the model. Those survivors who did not experience long-term effects of treatment like pain (OR, 3.11; 95%CI 1.16-8.35) and fatigue (OR, 2.6; 95%CI 1.05 to 6.48) were found to have optimal work ability

4.2.1.3 Depression among breast cancer survivors(n=209)

4.2.1.3a Prevalence of depression among breast cancer survivors (n=209).

This chart (Figure 4.8) describes the present level of depression among survivors.

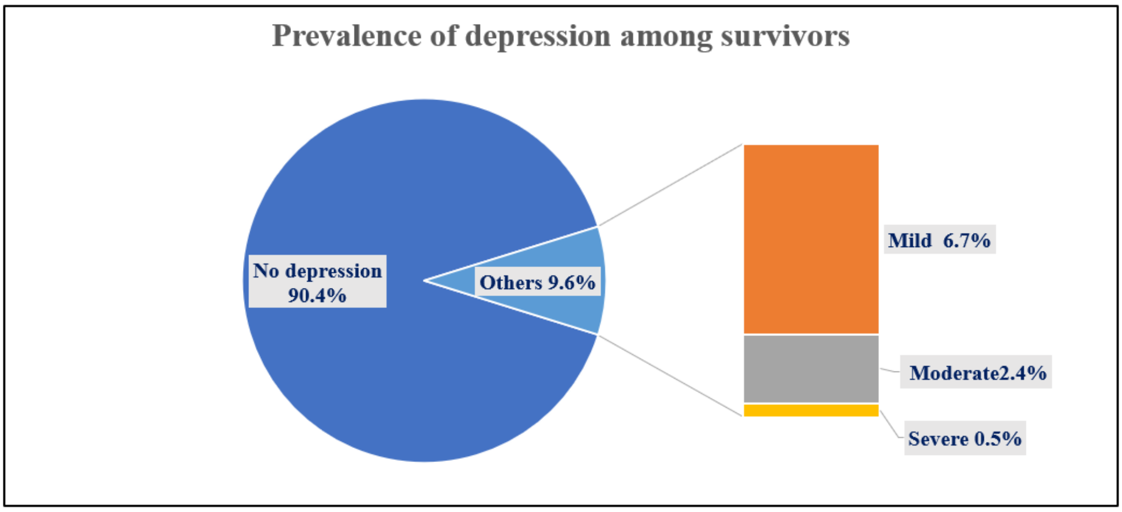


Figure 4.7 Prevalence of depression among breast cancer survivors(n=209)

Data were collected using a PHQ 9 scale of depression. Among study subjects, it was found that 90.4% had no depression, 6.7% had mild levels of depression, 2.4% had moderate and 0.5% had severe depression. The categorization was based on the scoring system of the PHQ 9 scale. The total scores ranged between 0 to 27. Cut-off points of ≥5, ≥10, and ≥15 represent mild, moderate, and severe levels of depression. The prevalence of depression among our study participants was 9.6%.

For further analysis, two categories were created ‘No depression’ (score <5) and ‘Depression’ (score ≥5) as described in methodology section.

4.2.1.3b Factors associated with depression among survivors(n=209)

Bivariate analysis was done to find out the factors associated with depression among survivors. (Table 4.12). For cell values less than five, Fishers exact test was done, while in all others Chi-square test was done to determine associations.

The table 4.12 demonstrates the present level of depression among the study participants and the associated factors (n=209). For this analysis, the depression score was recoded as ‘No depression’ (score<5), and ‘Depression’ (score≥5).

Table 4.12: Depression and associated factors(n=209)

Variables	No depression (score <5) n (%)	Depression (score ≥5) n (%)	Chi-square test p-value
Education			
Below 5th std	31(91.2)	3(8.8)	1.00†
5th std and above	158(90.3)	17(9.7)	
Marital status			
Married	149(89.8)	17(10.2)	0.70†
others	40(93.0)	3(7.0)	
Parity			
Have children	173(91.1)	17(8.9)	0.10†
No children	9(75.0)	3(25.0)	
Comorbidities			
Yes	53(91.4)	5(8.6)	0.77
No	136(90.1)	15(9.9)	
Stage at diagnosis			
Early stage	142(88.0)	18(11.3)	0.17†
Late stage	47(95.9)	2(4.1)	
Type of surgery			
MRM	141(90.4)	15(9.6)	0.10
BCS	48(90.6)	5(9.4)	
Present age			
<50	63(95.5)	3(4.5)	0.13
≥50	126(88.1)	17(11.9)	

Table 4.12 ctd.

Variables	No depression	Depression	p value
Present job			
Employed	38(97.4)	1(2.6)	0.13†
Homemaker	151(88.8)	19(11.2)	
Fatigue			
yes	51(79.7)	13(20.3)	<0.001*
No	138(95.2)	7(4.8)	
Pain			
Yes	36(85.7)	6(14.3)	0.24
No	153(91.6)	14(8.4)	
Lymphoedema			
Yes	53(91.4)	5(8.6)	1.00
No	136(90.1)	15(9.9)	
Menstrual changes			
Chemo induced menopause	90(94.7)	5(5.3)	0.06
No change	99(86.8)	15(13.2)	
Hot flashes			
Yes	37(92.5)	3(7.5)	0.77†
No	152(89.9)	17(10.1)	
Osteoporosis			
Yes	53(88.3)	7(11.7)	0.60
No	136(91.3)	13(8.7)	
Mood changes			
Yes	75(84.3)	14(15.7)	0.009*
No	114(95.0)	6(5.0)	
Cognitive changes			
Yes	46(86.8)	7(13.2)	0.20
No	143(91.7)	13(8.3)	
Numbness/weakness of arm/legs			
Yes	49(87.5)	7(12.5)	0.42
No	140(91.5)	13(8.5)	
Present work ability			
Sub optimal	24(63.2)	14(36.8)	<0.001*†
Optimal	165(96.5)	6(3.5)	
Present disease status			
Disease free	184(92.5)	15(7.5)	<0.001*†
With disease	5(50.0)	5(50.0)	
Anxiety			
No anxiety	160(94.1)	10(5.9)	0.002*
Anxiety	29(74.4)	10(25.6)	

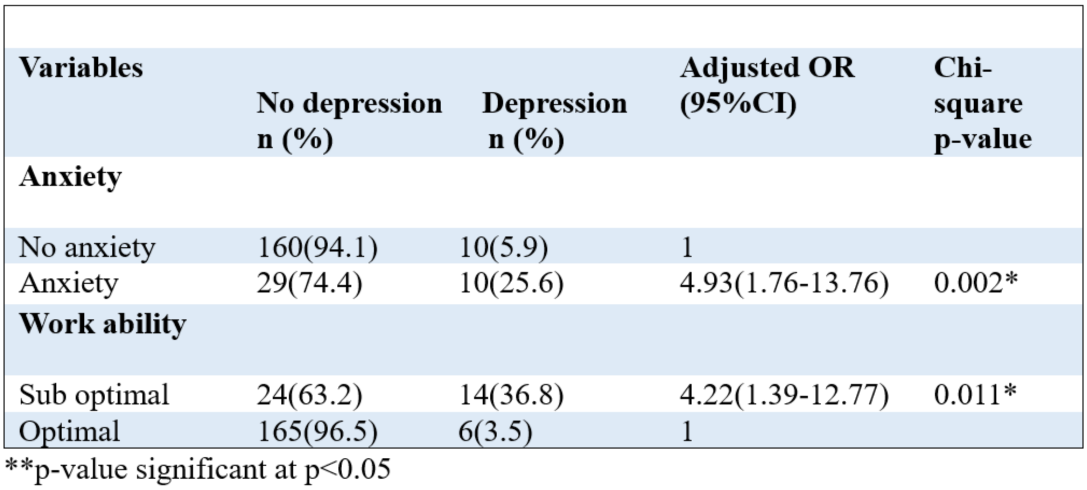
*p-value significant at p<0.05 † Fischer's exact test

It was found that long-term effects of cancer treatment like fatigue, treatment-induced menopause-associated mood changes, present disease status, self-assessed work ability, and anxiety were significantly associated with depression among survivors. Other factors like education, marital status, parity, comorbidity, stage of diagnosis, type of surgery, age, occupation, long-term effects of cancer treatment like pain, lymphoedema, treatment-induced menstrual changes, hot flashes, osteoporosis, mood changes, cognitive issues, and numbness or weakness of arms and legs did not have any significant association.

4.2.1.3c Factors associated with depression using binary logistic regression analysis

Further analysis was done to find out the factors which can predict a model of association between depression and other possible predictor variables. The outcome variable was depression, a dichotomous variable. The categories included “No depression” and “Depression”. The independent variables were “work ability”, “present disease status”, “anxiety”, “fatigue” and “mood changes”. These variables were those in which a significant statistical association was obtained in the bivariate analysis (Chi-square test, p-value <0.05). These variables were also found to be associated to depression as evidenced by the literature. Further analysis was done after examining the various assumptions to be satisfied. The correct fitness of the model was indicated by the Hosmer and Lemeshow test ($\chi^2(6) = 1.933, p=0.926$). The selected independent variables underwent the process of repeated deleting, refitting and verification process before the adequate model of fit was identified.

Table 4.13: Summary of binary logistic regression analysis for variables predicting depression among survivors(n=209)



Variables	No depression n (%)	Depression n (%)	Adjusted OR (95%CI)	Chi-square p-value
Anxiety				
No anxiety	160(94.1)	10(5.9)	1	
Anxiety	29(74.4)	10(25.6)	4.93(1.76-13.76)	0.002*
Work ability				
Sub optimal	24(63.2)	14(36.8)	4.22(1.39-12.77)	0.011*
Optimal	165(96.5)	6(3.5)	1	

**p-value significant at $p<0.05$

The adequately fitting model identified had Model coefficient ($\chi^2(6)$ =21.138, p=.002, -2 Log Likelihood=110.748, Nagelkerke R square= .206 and overall percentage of 90.4.

Logistic regression analysis was performed to see if work ability, disease status, anxiety, fatigue, and mood changes were predictors of depression among survivors. It was found that having anxiety (mild/moderate or severe) was a predictor of depression among survivors (OR, 4.93; 95%CI 1.76 to 13.76) when compared to those without anxiety. Survivors with sub optimal work ability have more likelihood of depression than those with optimal work ability (OR, 4.22;95%CI 1.39 to 12.77). Thus, as per the model, sub optimal work ability and the presence of anxiety were predictors of depression after controlling for fatigue, mood changes, and present disease status.

4.2.1.4 Anxiety among survivors

4.2.1.4.a: Prevalence of anxiety among breast cancer survivors(n=209)

Figure 4.9 describes the present level of anxiety among the study participants (n=209). Data were extracted using a GAD 7 scale to measure anxiety.

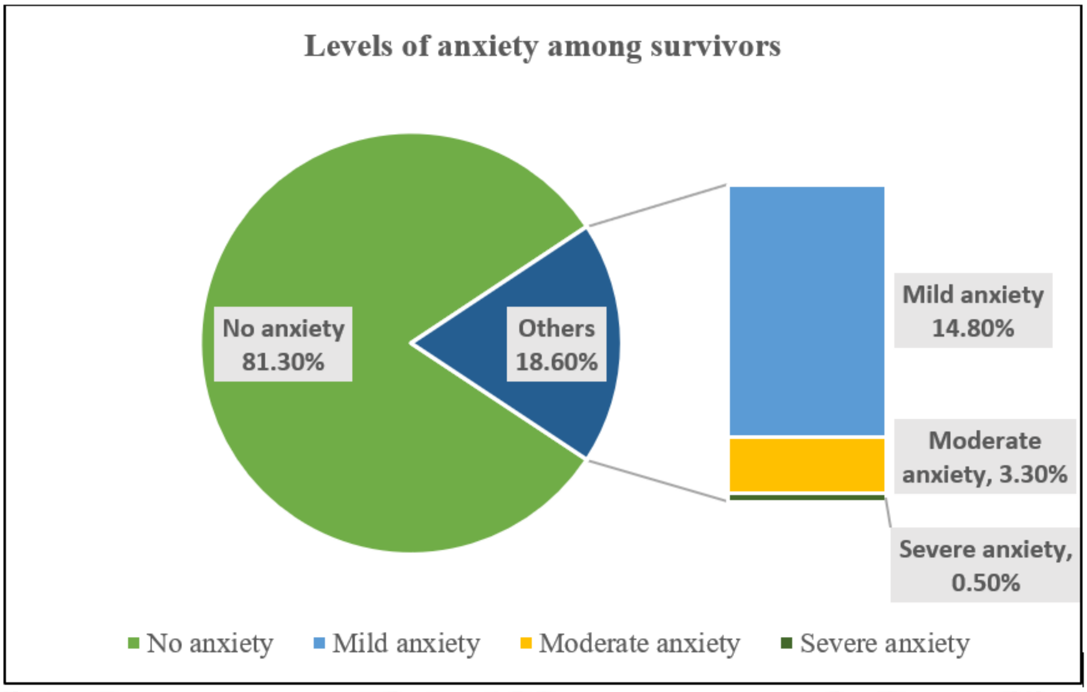


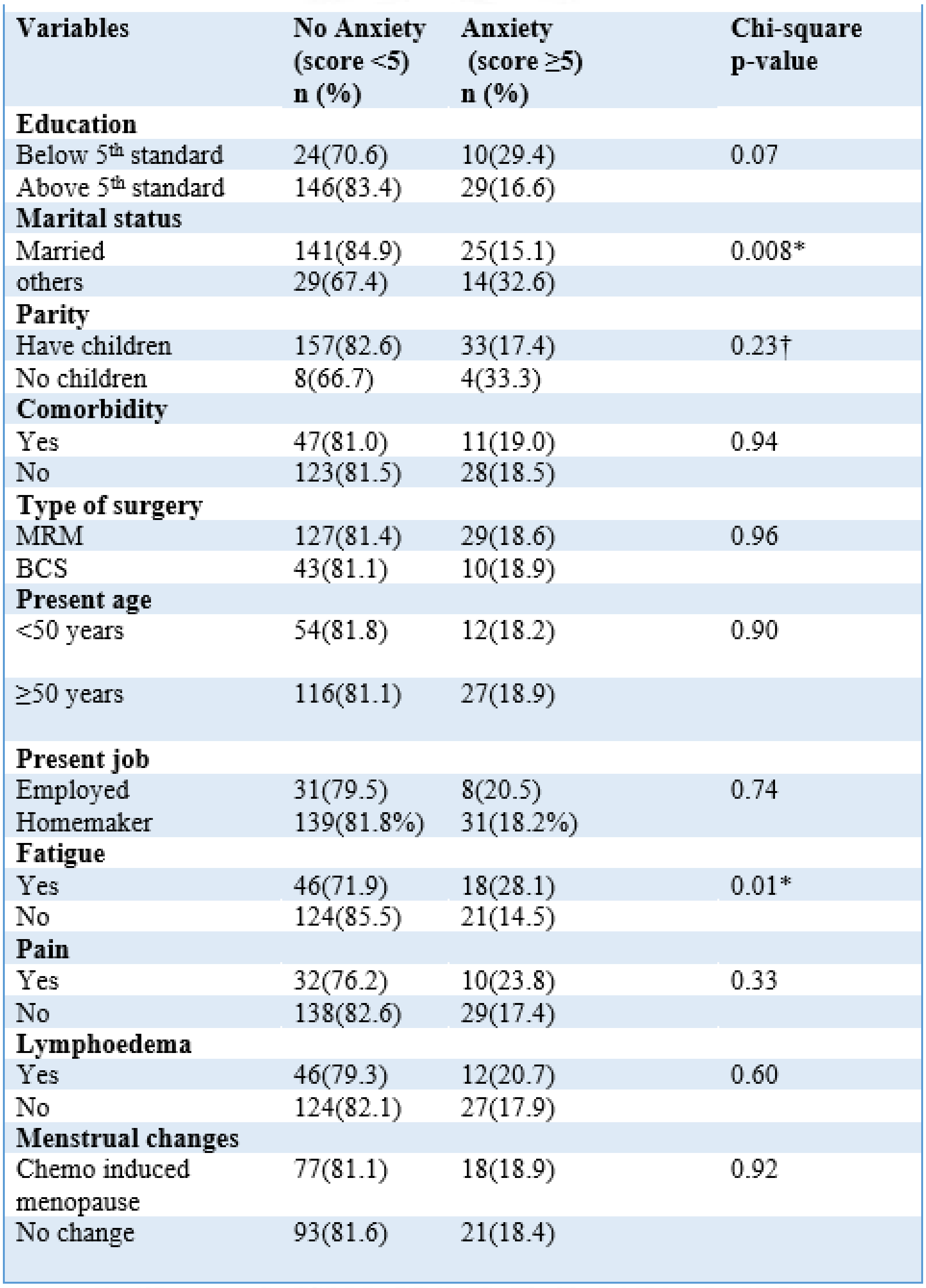
Figure 4.8: Prevalence of anxiety among breast cancer survivors(n=209)

It was found that 81.3% had no anxiety,14.8% had mild levels of anxiety,30.3% had moderate and 0.5% had severe anxiety. The categorization was based on the scoring system of the GAD 7 scale. The total scores ranged between 0 to 21. Cut-off points of ≥5, ≥10, and ≥15 represent mild, moderate, and severe levels of anxiety. The prevalence of anxiety among study participants was 18.6%.

4.2.1.4b Factors associated with anxiety among survivors(n=209)

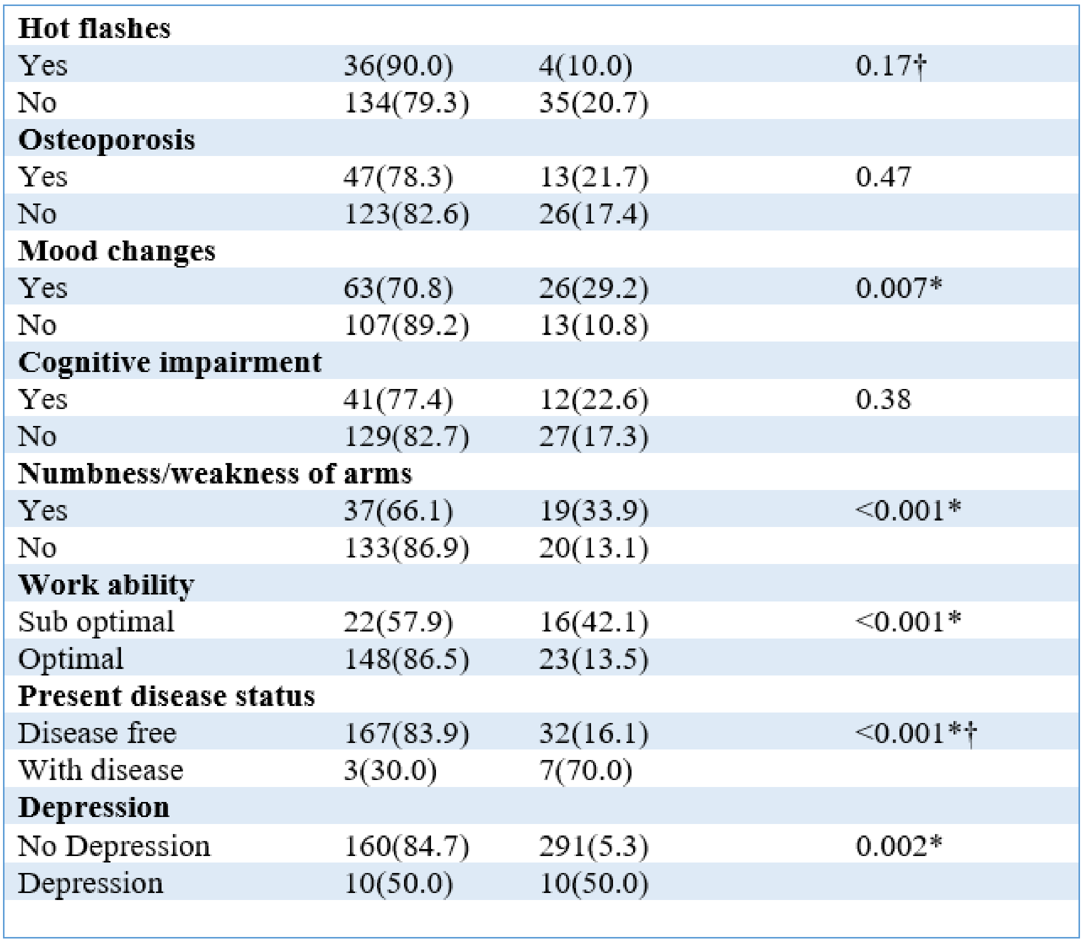
The factors associated with anxiety among survivors were studied using bivariate analysis. Table 4.14 demonstrates the present levels of anxiety among the study participants and the associated factors (n=209). For this analysis, the anxiety score was recoded as ‘No anxiety’ (score<5) and ‘Anxiety’ (score≥5) as mentioned in the methodology.

Table 4.14: Anxiety and associated factors among survivors(n=209)



Variables	No Anxiety (score <5) n (%)	Anxiety (score ≥5) n (%)	Chi-square p-value
Education			
Below 5th standard	24(70.6)	10(29.4)	0.07
Above 5th standard	146(83.4)	29(16.6)	
Marital status			
Married	141(84.9)	25(15.1)	0.008*
others	29(67.4)	14(32.6)	
Parity			
Have children	157(82.6)	33(17.4)	0.23†
No children	8(66.7)	4(33.3)	
Comorbidity			
Yes	47(81.0)	11(19.0)	0.94
No	123(81.5)	28(18.5)	
Type of surgery			
MRM	127(81.4)	29(18.6)	0.96
BCS	43(81.1)	10(18.9)	
Present age			
<50 years	54(81.8)	12(18.2)	0.90
≥50 years	116(81.1)	27(18.9)	
Present job			
Employed	31(79.5)	8(20.5)	0.74
Homemaker	139(81.8%)	31(18.2%)	
Fatigue			
Yes	46(71.9)	18(28.1)	0.01*
No	124(85.5)	21(14.5)	
Pain			
Yes	32(76.2)	10(23.8)	0.33
No	138(82.6)	29(17.4)	
Lymphoedema			
Yes	46(79.3)	12(20.7)	0.60
No	124(82.1)	27(17.9)	
Menstrual changes			
Chemo induced menopause	77(81.1)	18(18.9)	0.92
No change	93(81.6)	21(18.4)	

Table 4.14 ctd.



Hot flashes			
Yes	36(90.0)	4(10.0)	0.17†
No	134(79.3)	35(20.7)	
Osteoporosis			
Yes	47(78.3)	13(21.7)	0.47
No	123(82.6)	26(17.4)	
Mood changes			
Yes	63(70.8)	26(29.2)	0.007*
No	107(89.2)	13(10.8)	
Cognitive impairment			
Yes	41(77.4)	12(22.6)	0.38
No	129(82.7)	27(17.3)	
Numbness/weakness of arms			
Yes	37(66.1)	19(33.9)	<0.001*
No	133(86.9)	20(13.1)	
Work ability			
Sub optimal	22(57.9)	16(42.1)	<0.001*
Optimal	148(86.5)	23(13.5)	
Present disease status			
Disease free	167(83.9)	32(16.1)	<0.001*†
With disease	3(30.0)	7(70.0)	
Depression			
No Depression	160(84.7)	291(5.3)	0.002*
Depression	10(50.0)	10(50.0)	

*p-value significant at p<0.05 † Fischer's exact test

Where ever cell values were less than five, Fisher's exact test was done, while in all others Chi-square test was done to determine associations It was found that marital status, fatigue, mood changes, numbness, work ability, present disease status, and depression were factors associated with anxiety in the study (Chi-square test p value less than 0.05). It is seen that 84.9% of women who were in a marital relationship had no anxiety. Similarly, those who did not experience fatigue were found to have no anxiety (85.5%). Those who did not experience menopause-induced mood changes (89.2%), and those without treatment-induced numbness and weakness of arms (86.9%) were found to have no anxiety when compared to those with these symptoms. Those with optimal work ability (86.5%) had no anxiety, while 42.1% of those with sub optimal work ability reported anxiety. Those who had no depression also reported having no anxiety. Survivors who were disease-free at present reported having no anxiety (83.2%), while (71.4%) of those with disease recurrence and undergoing treatment now, reported having mild to severe anxiety. Regarding education status, 29.4% of survivors who had below fifth standard education had mild to severe anxiety, while the majority (83.4%) who had above fifth standard education had no anxiety. However, this association was not statistically significance in our study.

Logistic regression analysis was done to find out predictors of anxiety with other variables. A good fit model could not be obtained even after repeated deleting, refitting, and verification.

4.2.1.4c: What do you feel is the cause of your anxiety?

An open-ended question was asked as to what the participants feel were their causes of anxiety. The responses obtained are given in the figure 4.10

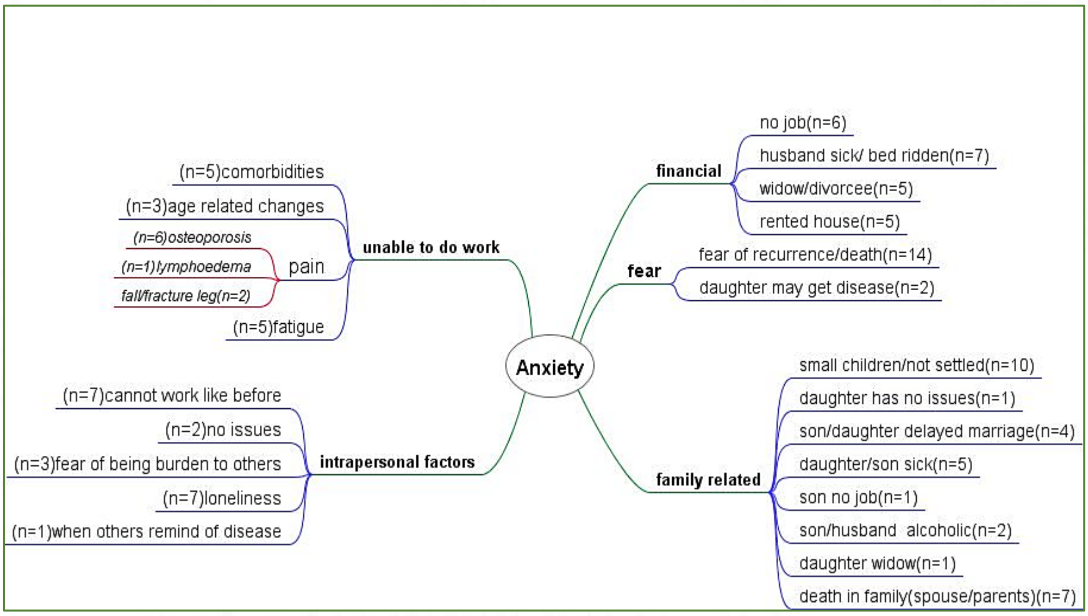


Figure 4.9: What do you feel is the cause of your anxiety?

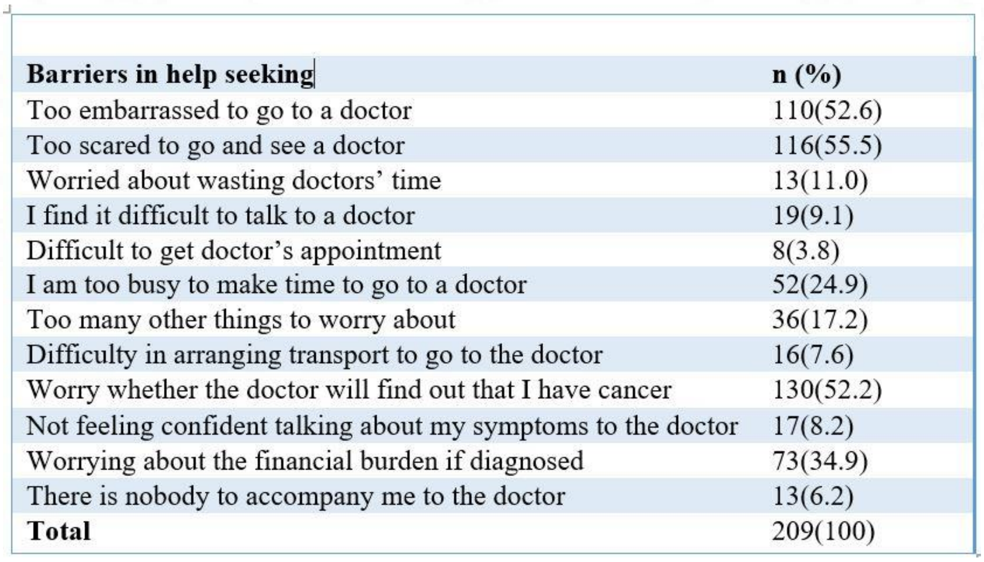
The above figure details the answers received when asked an open-ended question on what they felt was their cause of anxiety. The major themes which emerged were financial issues, family and self-related issues, fear, and worry regarding the inability to do any work. The most frequent answer was fear of recurrence or death. In addition, family issues, being unable to contribute to the family finance, being unable to work like before, the burden of family responsibility in widows and divorcees, loneliness in the unmarried, and fear of a daughter getting the disease were also mentioned. In most women, it was seen that they were worried of other factors more than their disease which contributed to their anxiety.

4.2.1.5: Barriers the women experienced in seeking medical help for breast symptoms before diagnosis

4.2.1.5.a Barriers to help seeking

Table 4.15 describes the barriers to help-seeking that the participants faced during the initial diagnosis of disease. The most commonly reported barriers were “too scared to go and meet a doctor”, “too embarrassed to go to a doctor “and worry whether the doctor will find out that I have cancer”

Table 4.15: Barriers to help-seeking reported by the survivors(n=209)



Barriers in help seeking	n (%)
Too embarrassed to go to a doctor	110(52.6)
Too scared to go and see a doctor	116(55.5)
Worried about wasting doctors’ time	13(11.0)
I find it difficult to talk to a doctor	19(9.1)
Difficult to get doctor’s appointment	8(3.8)
I am too busy to make time to go to a doctor	52(24.9)
Too many other things to worry about	36(17.2)
Difficulty in arranging transport to go to the doctor	16(7.6)
Worry whether the doctor will find out that I have cancer	130(52.2)
Not feeling confident talking about my symptoms to the doctor	17(8.2)
Worrying about the financial burden if diagnosed	73(34.9)
There is nobody to accompany me to the doctor	13(6.2)
Total	209(100)

"The financial burden that the disease might bring" and "I am too busy to make time to go to a doctor" were also seen. Many endorsed more than one barrier. "Difficult in getting appointment" was the least reported barrier.

4.2.1.5b: Barriers which you think delayed your help seeking process-Responses to the open-ended question.

Out of the 209 survivors 88.5%(n=185) responded to the question and endorsed one or the other barriers. Both positive and negative barriers were reported. The positive barriers delayed help-seeking, while negative barriers helped in early help-seeking. The positive barrier which maximum number reported was that they did not recognize the lump to be due to cancer (n=55). The other positive barriers which were reported by many respondents were painless lump(n=13), and family taking symptom very lightly(n=8). Among family-related matters, it was noted that if any of the family members is working in a health-related sector (hospital receptionist, hospital clerk, nurse, pharmacist) it helped in early help-seeking, family responsibilities delayed help seeking. Among provider-related factors, having a family physician or a familiar doctor helped in hastening help-seeking, while seeking alternative medicines(n=5) and non-recognition of symptoms from the part of the doctor was a positive barrier. Among intrapersonal factors, 'not disclosing symptoms to anyone', delayed help-seeking, while those who read health magazines and attended awareness classes sought help for their ailments without any delay. Those who had previous history of benign lump in self or family, mistook their symptoms as not cancer, and delayed help-seeking.

Fig 4.11 given below demonstrates the responses to the open-ended question. The study participants were asked "Can you think of any other reasons which delayed your process of consulting a health care worker?"

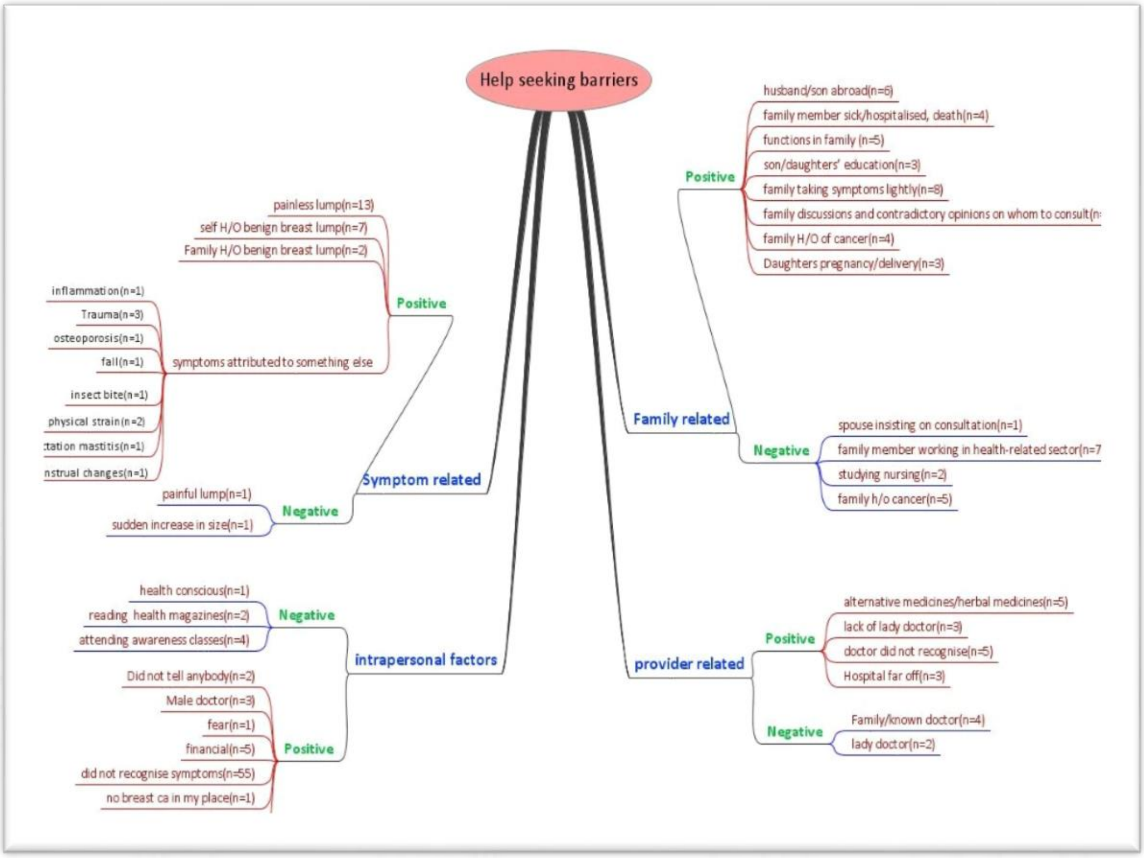


Fig 4.10: Barriers to help-seeking- "Can you elaborate on any barriers you faced during the help-seeking process?"

While painless lump was a barrier to help seeking, painful lump or sudden increase in size of lump hastened the help seeking process. Attributing the symptoms to something less serious was noted as a positive barrier. Non availability of lady doctor was also endorsed as a positive barrier to help seeking. Also, lactation was also reported as a cause of delayed help seeking.

4.2.1.5c: The time for the first consultation after the initial recognition of symptoms.

The women were asked the time they took to consult a Health Care Worker (HCW) after they recognized the symptoms. The responses are graphically represented.

Figure 4.12 shows the time for the first consultation as reported by patients after the initial recognition of symptoms.

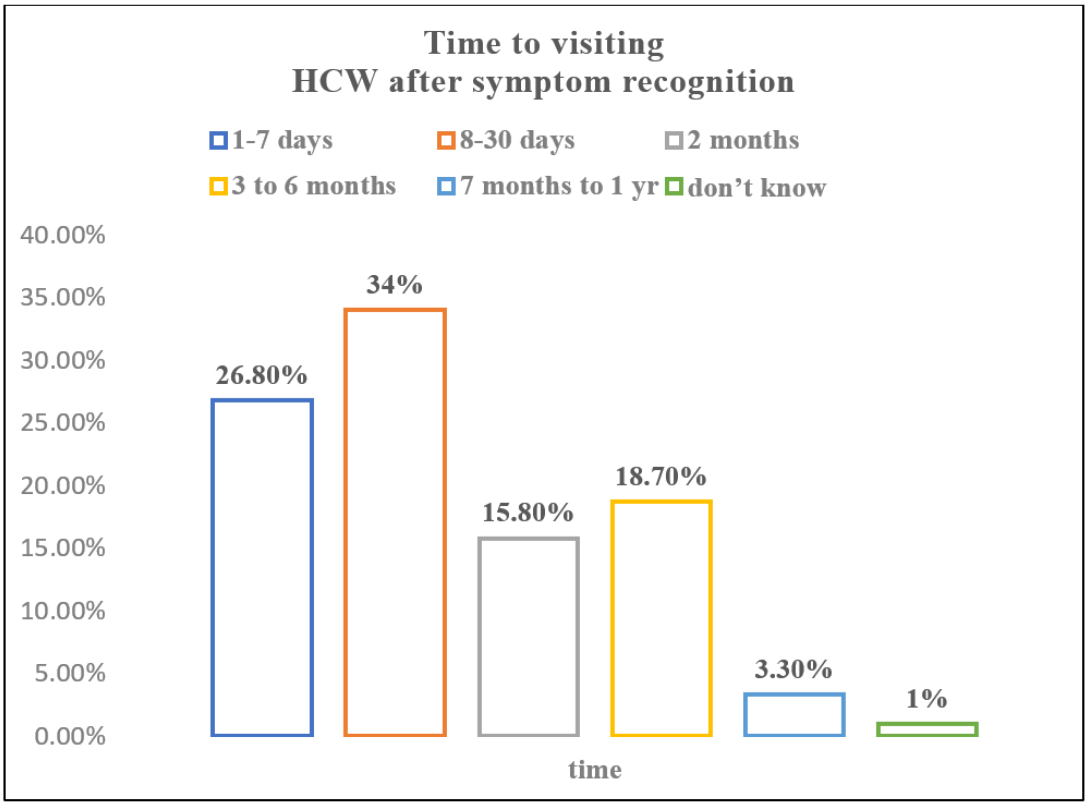


Figure 4.11: The time for the first consultation after the initial recognition of symptoms (n=209)

It is noted that 60% of the women visited a health care worker within one month of recognizing symptoms and 26.8% within one week. About 18.7% took three to six months for visiting HCW.

4.2.1.6: Awareness among breast cancer survivors regarding breast cancer

4.2.1.6a: Awareness about risk factors of breast cancer among survivors(n=209)

Figure 4.13 given below gives details regarding awareness about risk factors among the survivors.

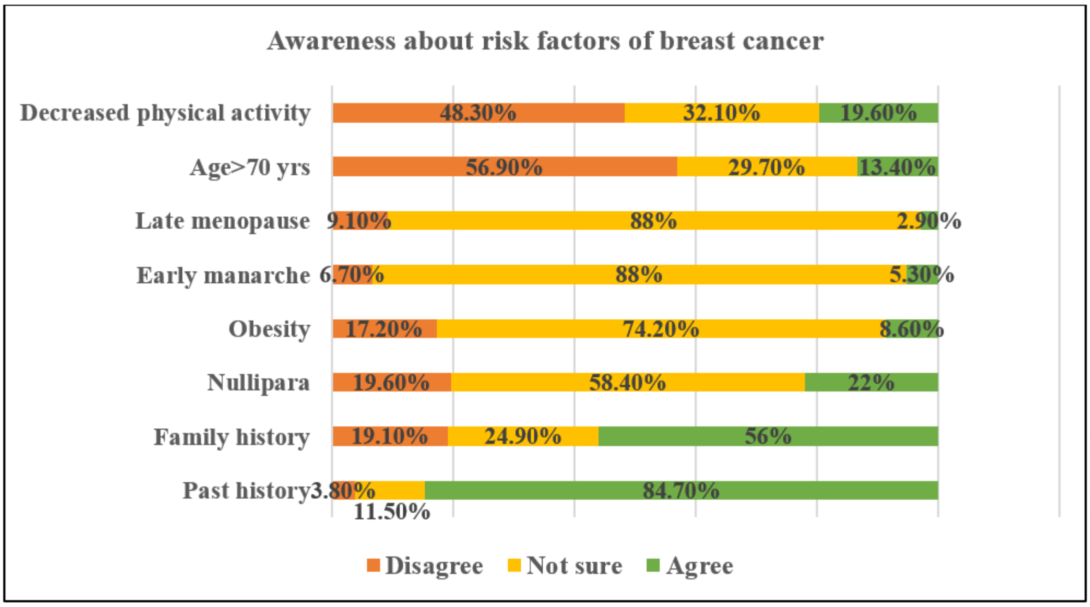


Figure 4.12: Bar chart showing awareness about risk factors of breast cancer among survivors

It can be seen that 84.7% are aware that a past history of breast cancer is a risk factor for oneself for developing breast cancer. Awareness regarding family history as a risk factor for breast cancer is seen in 56%. Awareness regarding other factors like not having given birth, obesity, early menarche, late menopause, age more than 70 years, and decreased physical activity was very less among survivors. Nearly 50% disagreed with the fact that an increase in age and decreased physical activity are risk factors for breast cancer.

4.2.1.6b: Factors which survivors perceived as the cause of breast cancer for them (n=209) in the open-ended question

An open-ended question was asked “Any other cause which you could think of was responsible for your breast cancer?”

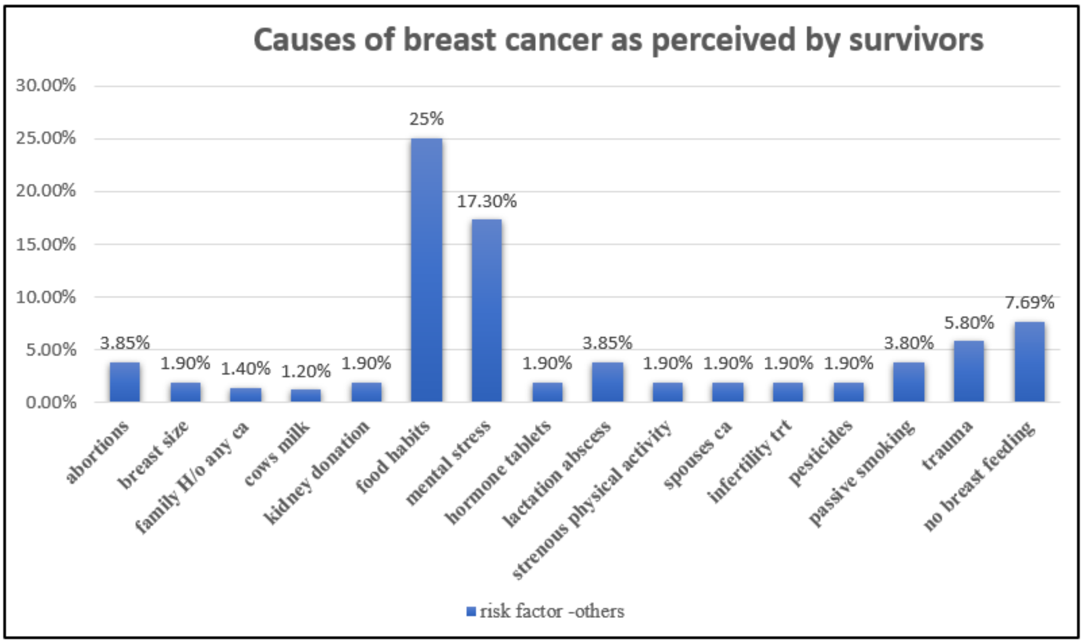


Figure 4.13: Bar chart showing responses to self-perceived risk factors among survivors

The majority (25%) reported food habits and stress (17.3%) as the cause of their breast cancer. Decreased breastfeeding as a risk factor was reported by 7.69%. Family history of cancer, pesticides, size of the breast, lactation abscess and passive smoking were the other reasons reported.

4.2.1.6c: Awareness of symptoms of breast cancer among survivors(n=209)

The participants were asked about their knowledge of the symptoms of breast cancer. Analysis of data regarding awareness of symptoms of breast cancer among survivors is shown in the bar chart (Figure 5.4).

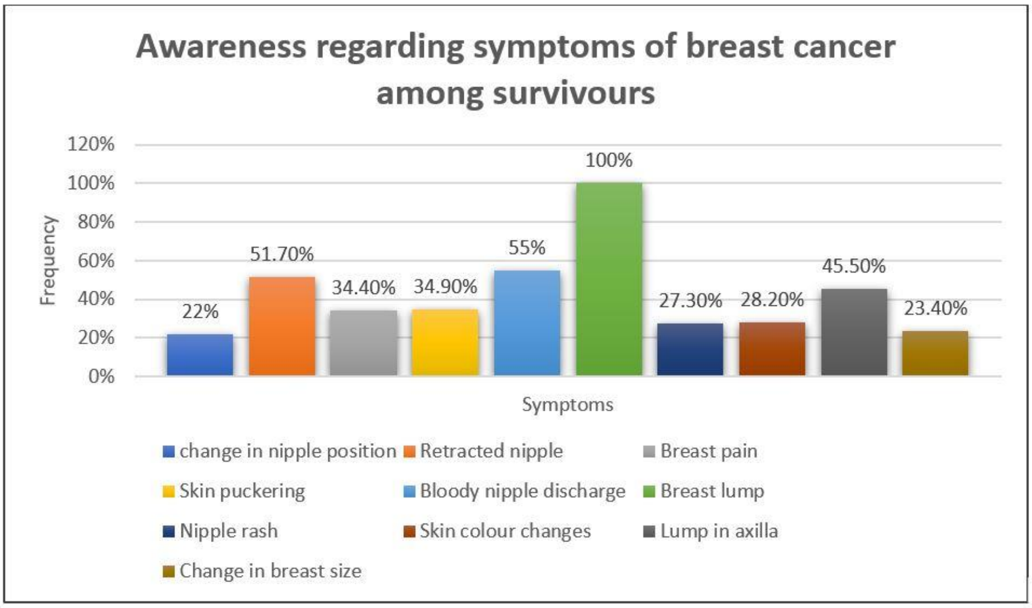


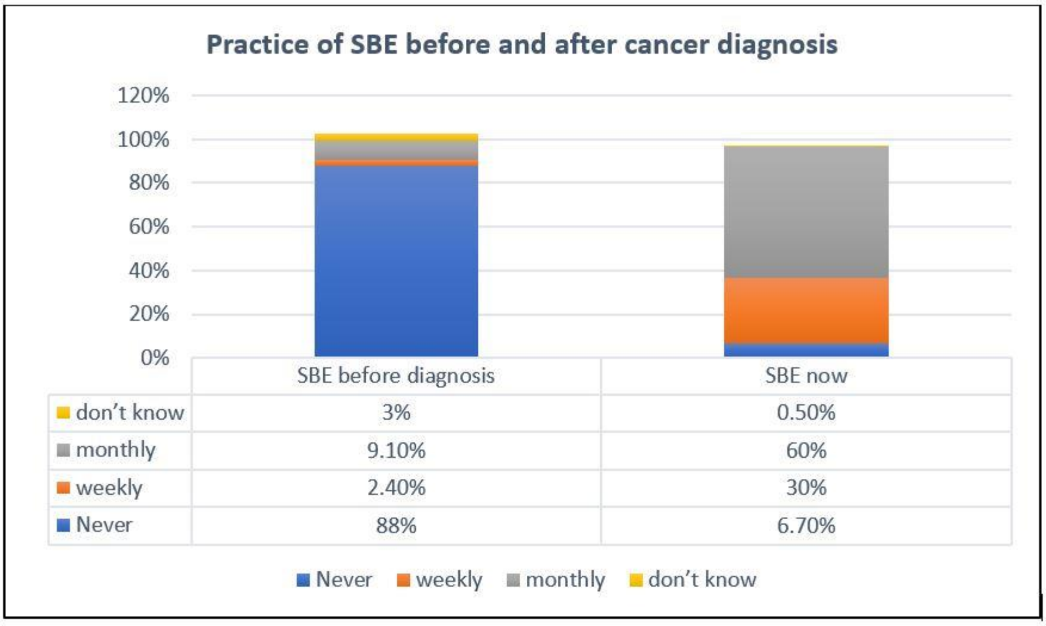
Figure 4.14: Bar chart showing awareness about symptoms of breast cancer among survivors

It is seen that all women (100%) were aware of the fact that a lump in the breast is a symptom of breast cancer. Other symptoms which the survivors were aware of, in decreasing order of frequency were discharge from the nipple (55%), a retracted nipple (51.7%), and a lump in the axilla (45.5%). Though, pain in the breast and puckering of skin were recognized as symptoms by more than 30%, awareness regarding many symptoms like change in nipple position, nipple rashes, skin colour changes, and sudden changes in the size of the breast was very less.

4.2.1.6d: Awareness about Breast Self -Examination (BSE) among survivors(n=209)

4.2.1.6d1: Practice of BSE among survivors (n=209)

Figure 4.16 shows the difference between practice of BSE before diagnosis and presently. among the survivors.



	SBE before diagnosis	SBE now
■ don't know	3%	0.50%
■ monthly	9.10%	60%
■ weekly	2.40%	30%
■ Never	88%	6.70%

Figure 4.15: Graph showing a comparison between the practice of BSE before diagnosis and now

It is noted that before diagnosis 88% confessed of never doing a Breast Self-examination. Only 12% examined their breast either weekly or monthly. About 90% reported that they examined their breasts either on a weekly basis (30%) or on a monthly basis (60%). A 6.7% of survivors confessed of never performing BSE even now.

4.2.1.6d2: Confidence of detecting a change in their breast by performing BSE among survivors (n=209)

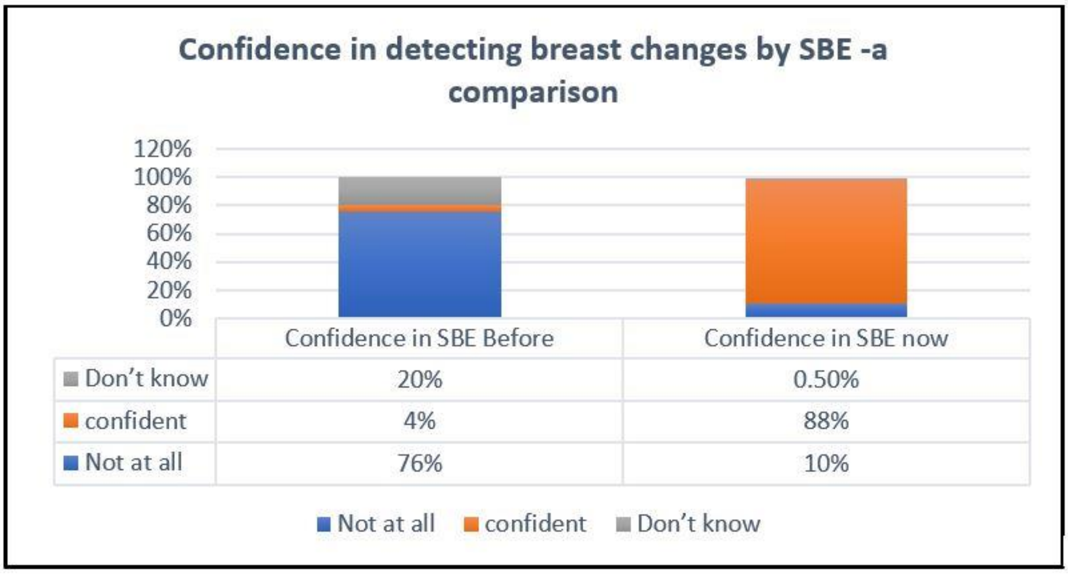


Figure 4.16: Graph showing a comparison between the confidence of detecting breast changes by BSE before diagnosis and now

Before being diagnosed with breast cancer 76% were not at all confident that they could detect changes in their breast by BSE. While now 88% of women are confident of detecting changes in their breasts.

4.3: Dimensions of survivorship and associated factors as synthesis

The figure 4.18 given below is a consolidated representation of the three dimensions of survivorship in the present study and the associated factors viz.

1) Work ability 2) Depression, and 3) Anxiety.

As clearly visualized in (Figure 4.18), 82% have good/excellent work ability, 90.4% have no depression, and 81.3% have no anxiety

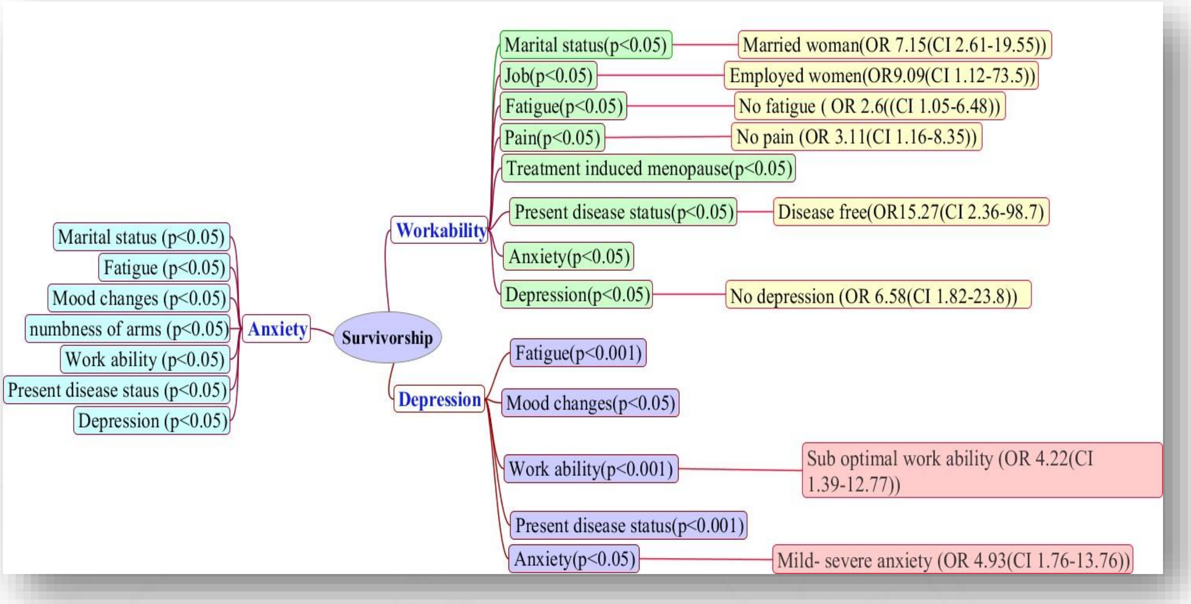


Figure 4.17: The dynamics of breast cancer survivorship and the dimensions

4.3.1: Work ability

Work ability is associated with marital status, job, fatigue, pain, symptoms due to premature menopause, disease status, anxiety, and depression in the bivariate analysis. All these factors in one way or another were affecting work ability; either contributing to or hindering the survivorship process. When further looked into the predictors in multivariate analysis, marital status, job, absence of pain, fatigue, and depression were found to be predictors of work ability, in turn affecting survivorship. The predictors are the first-level factors to be addressed for better survivorship.

4.3.2: Depression

Depression was associated with fatigue, mood changes, disease status, anxiety, and work ability on bivariate analysis. On multivariate analysis for assessing predictors, it was noted that sub optimal work ability and the presence of anxiety were predictors for depression.

4.3.3: Anxiety

Anxiety, on bivariate analysis was found to be associated with anxiety, fatigue, mood changes, numbness, work ability, disease status, and depression.

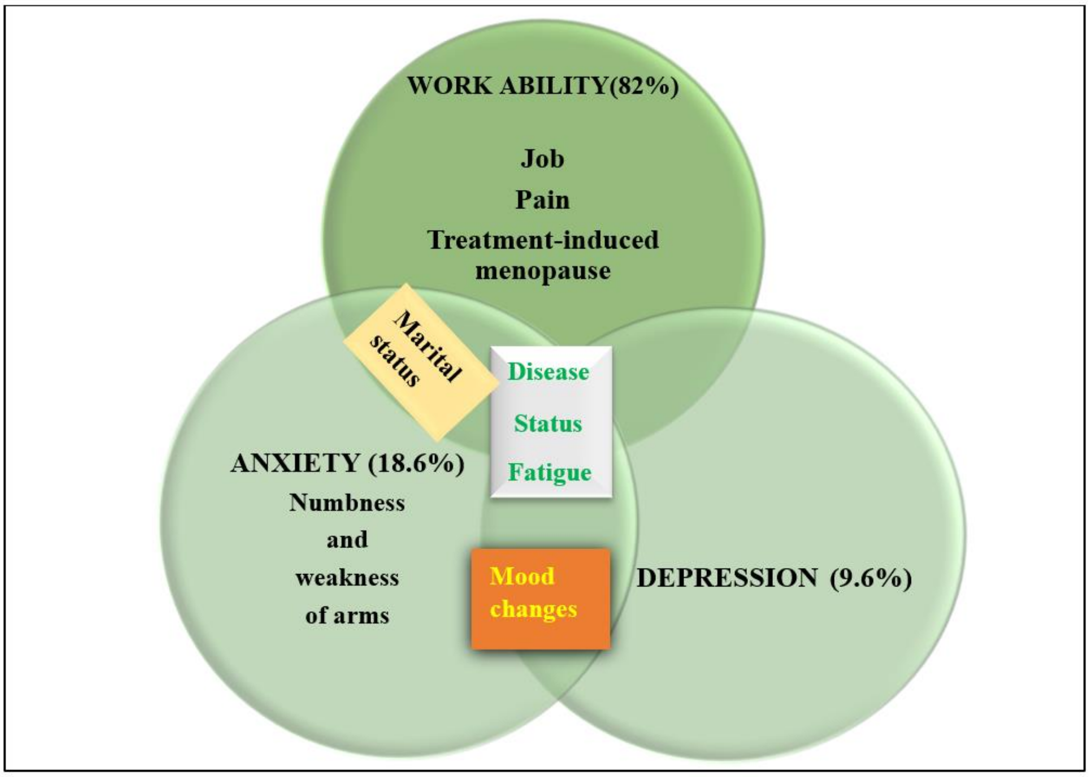


Figure 4.18: The dynamics of breast cancer survivorship and the dimensions-a synthesis

Figure 4.19 shows the findings on further analysis of the dimensions of survivorship. When we looked into the associated factors, they were associated with all three dimensions of survivorship. Few factors were common to all**.** On further analysis, it was found that the disease status and fatigue were associated with all three dimensions of survivorship in our study. Anxiety and depression were associated with mood changes. Mood changes are one of the symptoms associated with treatment-induced premature menopause seen in young survivors of breast cancer. Marital status was associated with work ability and anxiety. No common factors were associated between work ability and depression. Work ability is associated with both anxiety and depression. On synthesis, work ability, anxiety and depression, and the associated factors were found to be interrelated. Improving any one factor can result in improvement of other factors as well.

4.4: Findings of in-depth interviews

The qualitative component of the study presents the experiences of the survivors-a main aspect of survivorship. Among the beneficiaries of breast cancer care, the participants include those who are 1) presently disease free and 2) living with the disease. The findings of the qualitative study contribute to an important dimension to the larger survey among the participants in the Hospital Based Cancer Registry. This will uncover the unknown experiences of the survivors. As part of the analysis, the interviews that were conducted in Malayalam as per the interview schedule were transcribed and then translated to the English language. After language corrections, the translated English transcript was coded following axial coding. These were further grouped as per the emerging cluster of themes. These themes were further categorised, and were consistent with the quantitative findings as well. The patterns emerging from the qualitative analysis may give further information on various aspects of survivorship.

Two groups were interviewed as part of the qualitative part of the study. The survivors were selected from the participants of the follow up survey. The first group of survivors were those who had undergone treatment in 2016 and were disease free in 2022. The second group were the survivors who had undergone treatment in 2016 and are having recurrence in 2022.

4.4.1: In-depth interviews among survivors who were disease free

4.4.1.1: Introduction

In-depth interviews were conducted among survivors to explore the survivor experiences and living with disease experiences among them. The total number of survivors interviewed was fifteen, who were at present free of disease in 2022 and under follow-up. The age range of the survivors was from 44 to 67 years. All except one were married and had children. One was a widow. Three of them were working, one was doing an office job, other was a manual labourer and third was a teacher. Ten of them were having stage 2 disease and five were having stage 3 disease when interviewed.

The survivors were asked about the following: their present thoughts and experiences of the disease, whether they were planning to return to work or have already returned to work/ resumed their daily activities including household chores. If started working, their experiences on returning to work regarding the same, experiences due to the stigma prevailing in the society regarding cancer, their perceptions regarding revealing their illness to others, their views on survivorship and challenges faced by them, whether they were engaged in supporting other patients who sought treatment for breast cancer.

(*The names used in the narratives are not real)

4.4.1.2: Findings

The following were the different themes that emerged from the analysis

4.3.1.2.1: Am I a survivor??

As per the literature, most women do not want to be identified as 'cancer survivors' due to the feeling of victimization associated with the word. Contrary to the studies published, none of our survivors expressed such concern, though various other thoughts were associated with it. Different women had different perspectives about survivorship.

4.3.1.2.1.1: Conquering cancer

54-year-old Mrs. Valasla stated: *"Yes, I am a survivor. In spite of the difficulties experienced due to the disease and the treatments, I managed to survive 6 years"*

According to Mrs. Valsala, from a rural area of north Kerala, the one who lives disease-free longer is a survivor.

Similarly, Mrs. Uma a 44-year-old survivor, from a grama panchayath in north Kerala mentioned:

"When I first came to the cancer centre, I did not even know whether I would be cured and live again after getting the disease"

Uma's words are suggestive that, the very fact that she is alive means that she is a survivor.

Mrs. Krithi aged 52 years, from a panchayath in the urban area in the district said:

"I fought the battle of this phase of my life with courage. I think being a brave fighter is a survivor"

Mrs. Krithi, clearly perceived that being brave when one fights a battle against cancer is a survivor. Fighting the battle, being cured, and completing treatment as the meaning of survivor is also reported in other qualitative studies as well (Knaul et al., 2020).

Even when the woman accepts herself as a survivor, it is not of any benefit if society fails to recognise her as a survivor. This was the point discussed by 52-year-old Mrs. Panjamam, from a municipal area of the district. She stated *"While I want to be known as a survivor, people around me still consider me as a patient. This is very painful for me"*

Some other participants were finding it difficult to accept themselves as a survivor in its full dimension as stated by the above-mentioned survivors.

One of the participants Ujala, aged 53 years said:

"I would like to call myself a survivor, but I don't think I have fully conquered the disease. I always have the fear that the disease may come back to me"

The ongoing presence of 'cancer' in their daily life, prevents them from accepting themselves as a survivor.

The above statements quoted by the women give us their perception of the word 'survivor'. Some of them could relate the word to 'being disease free', 'being alive', 'being a fighter', and 'being brave' as stated above. At the same time, some feel there was always the fear of recurrence of the disease associated with the word.

The above dimension may throw light on survivorship. However, being a woman, it is not just sufficient to survive. Losing a part of her body that is a symbol of femininity, and not being sexually active at a very young age makes it difficult for her to accept herself as a woman.

4.3.1.2.1.2: What I have lost from my body cannot be brought back….

Body image, 'an internal representation of one's external appearance', is an important aspect of survivorship in a patriarchal society, and was linked to survivorship by some women**.** The changes in their body or complete removal of a body organ as part of cancer treatment is a disturbing experience for women. This was the highlight of the next narratives of the two young survivors.

"I had to remove my whole breast. I cried a lot then. Even today I feel sad whenever I think about it. What I have lost from my body cannot be brought back, and no dress can mask the loss". The emotions of Mrs. Leni who was 45 years now were clearly conveyed in her narrative.

The survivors were highly concerned about their bodily appearance as they firmly believe that they were continuously being watched and evaluated by others. The words of a survivor quoted below also proves this.

"I do not like to go to any gatherings. I find it difficult to face people though I did not have any bad experiences. I feel breasts are an important part of a lady and I don't like my body anymore" said Sanu aged 45 years from an urban background.

Though younger women were concerned about their body image, some women especially middle-aged perceived it differently. Though concerned, when given an option between body image and being disease free, they preferred the second option as stated by a 67-year-old.

"Initially, when the doctor told me that my entire breast had to be removed, I could not take it and I asked if removing the lump alone would cure me. When the doctor said that as per stage, there is a chance of the disease coming back again. I immediately consented, as my life was more important than anything else at that

time". It is clear from the statement of Mrs. Naina, that her meaning of survivorship was to live long for her dear ones.

Two other survivors perceived it differently *"For me, the doctor said that I am in the early stage and removal of the lump alone would cure me. But my relatives said I should not think of such things now. Seeing to it that the disease does not come back is more important. My feelings were not important at that time. But I regret deeply now"* said 52-year-old Krithi.

Another survivor stated that*" It was my decision to remove the entire breast, though a breast-conserving surgery would have been enough for me"* said 52-year-old Vanija.

Being helpless due to fear of disease was the meaning of survivorship to these women. This forced them to consent to the removal of entire breasts for getting cured, even when the decision was not their own.

"Though I felt very sad and depressed at that time, I don't think much about I now. I have learned to accept this also as a part of my life"

The statement made by this 45-year-old Sanu, tells us that most women have learned to accept the changes in their body. Coping up and moving forward either for themselves or to conceal their feelings from the family members was their underlying perception of survivorship.

Accepting and enduring their new normal life was survivorship according to Mrs. Malli 58 years *"We build a house in our hometown. I also started to travel a lot, enjoy music, and interact with my friends through WhatsApp groups. My son is my greatest motivator, support and is the reason for my new life.".*

A 45-year-old mother Mrs. Leni said that *"Initially, I was not bothered about when I would die. I used to take it very lightly. But after getting the disease, I love my life more and now I want to live for my children"*

Though, some women speak of body image concerns and fear of recurrence, the hope of being disease free, and the urge to live long with their near and dear ones, helped them accept the changes, live their life to its full and move forward.

In addition to accepting the bodily changes, they also had to deal with changes that occurred in their sexual life, that was caused due to the disease or the treatment.

4.3.1.2.1.3: Post-treatment sex life

That body image concerns were related to sex life, was reported by some survivors. Even though they conquered the disease, life was not normal for the young survivor.

A 44-year-old Mrs. Uma, whose breast was removed as part of treatment said *"My sex life is normal, but I feel guilty, even though my husband is very understanding and supportive. I feel that I am not a complete woman anymore".*

Another survivor Sanu who was 45 years, said *"Though my sex life was not affected by the disease, I am not interested anymore. I feel uncomfortable"*

A sense of guilt was arising in these women, due to their perception of body image decreasing interest in their sex life, though they could resume their intimate relations after treatment.

"I am no longer interested in sexual relationship. I am afraid that my husband will get the disease, even though I know that it is not true." said a young survivor, 45-year-old Sreni.

Lack of awareness or despite being aware, fear of their spouse also getting the disease haunts these women.

One lady, 48-year-old Kani, stated that *"All these years have passed by and now I think more about my children and want to live for my family. All other things are not my priority anymore"*

Though women reveal that their sex life was not affected by the disease due to support and understanding from their spouses, they faced difficulties like pain and loss of interest due to guilt or a change of priorities.

4.3.1.2.1.4: My only prayer is that oh God! please protect me from the disease coming back…."

Even when they say that they are cured, survivors expressed their fear that the disease may recur at any time. The stories of others who had recurrence, caused anxiety in most of them as Krithi 52 years said:

"I am ok now and don't have much symptoms, but the fear of recurrence is always there at the back of my mind. Coming to cancer centre for follow-up is stressful and I don't feel relaxed until the doctor says that I am ok".

Survivors also reported that they feel relieved while coming to the cancer centre for follow-up and getting a thorough check-up. *"The very fact of coming here relieves me of my stress"*, stated 52-year-old Panjami.

Mrs Vanija thanked God and considered themselves lucky that they are disease free while stating the following:

"When I was admitted to the surgery ward, I have seen one lady with disease recurrence, on treatment. But I feel, I was lucky enough, so it did not come back. I cannot even think of going through the entire treatment again"

The fear of disease recurrence has made them think more carefully about their health. 45-year-old Leni speaks of the changes in her post-disease life as follows:

"I give more importance to my health now, do regular exercise, and also try to eat lots of fruits and vegetables. I do self-examination almost every day and go for check-ups without fail."

According to a 53-year-old Ujala, *"After I got this disease, I could never be the same person as before. I am never happy from the inside. There was always this weird feeling that I cannot express. I keep on telling myself that it will not come back."*

The fear of recurrence of the disease is a common feeling among survivors. Many visited the TCC for follow up and they believe that it will help them. They regularly do self-breast examinations, sometimes even on a daily basis, and are confident that they will be able to detect changes in their body. The fear has made them to realise the need for leading a healthy lifestyle.

But it seems that most women have learned to live with these thoughts or are ready to face things, as and when it comes. They feel that their life is not under their control as expressed by a 52-year-old Vanija:

"It is all up to God. Anyway, there is no use worrying too much. Whatever has to happen will come".

Fear of recurrence has led many to make healthy modifications in their lifestyle and undergo follow-ups regularly. They are thankful for their disease-free life and consider themselves lucky. Those for whom regular check-ups were stressful, they tried to find solace and relief in prayers. Few women were ready to accept that whatever is going to happen in future is their fate.

4.3.1.2.2: The survivor and stigma

Women feel that their lives were permanently changed after cancer, and as they strive hard to resume their routine life and work, their greatest expectation is support from family, friends and the society.

"My neighbours supported me well during my disease journey. Initially, when I was diagnosed, they regularly brought me my favourite food, gifted me with new dresses, and so on. This special preference made me feel as though I was going to die soon. I always tried to smile and make them feel that I am ok. I didn't like sympathy". This was expressed by a 45yr old Leni with early-stage breast cancer.

Cancer is a disease associated with stigma. In general, society looks at 'cancer' as a terminal disease and death sentence. Most often people express their support in weird ways.

Krithi, mother of two, said during the interview: *"My family including my in-laws supported me very well. Sometimes I feel uncomfortable due to their over-caring attitude and sympathy"*

On the other hand, those who are closest to you and who should have been your greatest support often did not know how to deal with the condition of their near one.

"My dearest friends kept apart, maybe they did not know how to face me or deal with my condition, but my colleagues frequently visited me, helped and supported me throughout", said 44-year-old Uma.

The mother of two children 54-year-old Valsala said:

"I was already on treatment for heart disease, and now I am diagnosed with cancer too. My first thought was that my husband would abandon me. On the contrary, he supported me the most"

Most women reported that they have received good support from their near and dear one, but stated that they hated the sympathy shown by people towards them. They said they their love and care were valued very much. Sometimes immense support was received from unexpected relatives and colleagues.

4.3.1.2.2.1: Selected quotes by the survivors on the support during treatment

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Quote 1: *"I used to wear a cloth to cover my hairless head during treatment. When my hair just started growing, my granddaughter said "Ammamma, don't use that cloth again". I asked her "Won't you feel ashamed of me?" "No. Why should I feel ashamed? This is normal during treatment." After that, I never covered my head".*

Quote 2: *"My husband could not cope up with my diagnosis. He was always silent after that. One day while I came back after my radiation treatment, he was found hanging in the bed room. I was completely shattered, as I had to undergo treatment as well as take the responsibility of my family"*

Quote 3
“*My greatest support was my two sons-in-law”*
“If only my wife’s disease is transferrable, I would have accepted it happily.”

“A husband who has concern about his wife and children who understand the meaning of motherhood are my strengths, which helped me overcome cancer.”

“The parents of my students visited me and gave moral support”

However, a few had bitter experiences too. A 45-year-old survivor reported that*” I was traveling by bus when I was taking chemotherapy. I had hair loss. One lady came and sat near me on the bus. It was only after some time that she saw me. She immediately got up and shifted to another seat. I cried a lot on that day”.*

“My prayers are that my disease does not come back at least until my daughter’s marriage, I fear her marriage will be affected” are the words of a 52-year-old survivor, Krithi.

Even though awareness about breast cancer has improved a lot, fear and misconceptions still exist in the society. Those with the disease often experience discrimination. While the woman is battling breast cancer, the interference from society, in a manner that is not acceptable to them, makes them lose courage.

4.4.1.2.3: Socioeconomic support

There are various treatment schemes of the Government that support cancer care. It is easy for a person who is already enrolled in the health insurance scheme to avail them, by submitting a few documents. Most of the women were not aware of the same.

“I had done surgery from a private setup as per the decision of my family. It was very expensive. I continued my further treatment from the TCC, and all my expenses were covered by the government treatment scheme “Karunya Benevolent fund”.

Another survivor who took the entire treatment from TCC said that" *I did not even have to spend a single rupee for treatment. I got the benefit of treatment schemes. But, now, the expenses for the follow-up mammogram and hormonal medicine, have to be paid by me. We have to continue these medicines for 5-10 years. Only if these were covered too…."*

The words of Panjami and Leni speaks about the benefits from treatment schemes. Most women have to take certain medicines like Tamoxifen for almost 10 years to prevent recurrence. They also have to undergo mammograms annually, which is also not covered under any schemes, in addition to the travel expenses. This fact can be understood from the words of this survivor. Though a small amount is available as a cancer pension annually, most women said that it is not distributed regularly.

"I could not go to work. My husband was a peon, so I was denied government treatment scheme also. Hence, I could not take a costly medicine, which would help prevent recurrence".

Even though these schemes cover primary treatment expenses, they are not available for all types of medicines, and post-treatment tests as stated above. Most of the Government health schemes available in India do not cover all medicines or have limited coverage (Haitsma et al., 2018), and lead to high out of the pocket expenses(Fan et al., 2015). Expenses for certain medicines not included in the scheme have to be borne by self, which sometimes may not be affordable.

"I went to a private hospital when my relative recommended a doctor. Later we came to know that the surgery was done by another doctor. That there are different modalities of treatment and for each one there are different doctors-all these were not known to me" said 54-year-old Valsala.

Though, treatment facilities are available in the Government setup, most people are not aware of the same. Some approach private hospitals for treatment under recommendation from relatives as the above survivor has stated. Out-of- pocket expenditure is three times higher for private inpatient cancer care in India (Smith and Mallath, 2019). They end up in financial loss after taking expensive treatment. Most people also do not know that the expenses in the government setup is covered by treatment schemes as explained by this survivor.

4.3.1.2.4: Social expectation

Cancer surgery and other adjuvant treatment cause many long-term and late health effects as reported in the literature (PV Gadgil et al., 2015), and as seen in our study.. This may pose difficulties even in their social normal duties.

"I was working in a small printing press. The work involves continuous lifting movements of the arm, which I cannot do now. I quit my job, though my employer calls me. I think I am now doing only 70% of the work compared to the past", said 53-year-old Ujala pointing to the swelling of the right arm. The presence of lymphedema, as a result of the surgery was reported by other study participants also.

Even those who wish to work could not do so due to other factors associated with family and work place as stated below.

"I don't like to depend on others. But my family does not permit me to go as my office is located far off".

Some reported getting good support from their colleagues. They also expressed their happiness about being able to give financial support to the family. The 45-year Sanu is happy about the favourable environment at her workplace.

"Initially I had to stop going to work. After one year of treatment, I went back to work. I am a manual labourer. My colleagues help me with my work. I am happy that I can financially support my family"

Such support from employers has also helped the survivors a lot in continuing their jobs as stated by 44-year-old Uma.

"I have been working away from home in a distant place before treatment. Even now I am continuing in my job, but switched to 'work from home' post COVID. My employer also permitted me to do so".

It is seen that sometimes the survivor themselves are concerned about their health and avoid doing strenuous work or the concern from the side of the family members prevents them from doing work that they enjoy

"My husband and children don't allow me to do any household work. It is difficult to sit idle at home. So, I take pain medication and do gardening work which I like to do"

"I don't do any strenuous jobs now. My husband always helps with everything. I also don't want to do any strenuous work, just to be safe."

Work has not only been a financial support to survivors but also relieve them of their stress and anxiety.

"Going to work decreases my tension. I feel happy as I forget about my disease" said 52-year-old Panjami.

Thus, survivors have expressed their desire to return back to work whether it is household chores, day-to-day activities, or paid jobs as it gives them satisfaction, happiness, stress relief, and financial support. A good workplace environment and support from employers, colleagues, and family are commonly mentioned by the survivors.

4.3.1.2.5: Service provision-related experiences and expectations

Breast cancer patients have to undergo follow-ups with regular breast examination and mammograms at routine intervals for many years, though the interval of follow-up increases with time. At present, they undergo follow-up in the routine breast OPD of the TCC. When asked whether they have any suggestions regarding any other facility they need during their follow-up, they came up with various requirements.

"We get a lot of information from others than we get from doctors. But we are not sure whether it is true or not. If doctors give us more information, it would have been better. For that, we need to spend more time in OPD", as quoted by 45-year-old Leni

Survivors expressed their opinion that they would like to get genuine advice from health workers rather than a layman. In a common busy outpatient department, doctors do not get more time to talk to them. This concern was also shared by another survivor, 67-year-old Naina.

"We would like to know what type of food we should eat, what exercises to do, etc. We would also like health workers to discuss about our other difficulties experienced in addition to regular check-ups.

"I thought that sexual life is not possible after treatment. Nobody told us about such things", said 44-year-old Uma

The distance was also a major concern. Many said that if situations like COVID arise, they cannot come to the TCC. Instead, it would be convenient, if such facilities were available in the primary care settings near their home. This was stated by 58-year-old Malli.

"During the COVID period, I felt that if some follow-up facility was available near my place, it would have been better. In the follow-up OPD, if the doctors also tell us about the symptoms we should look for if the disease recurs in any other parts of the body, we could at least check. We know this is not possible in an overcrowded OPD where patients on treatment are also cared for".

"It would be good to have a counselling facility in our OPD. It would also be good if a follow-up facility is available near our homes. Even for minor illnesses, we have to come to the TCC as doctors in our place don't attend to us"

It is clear from the above statements that an accessible follow up facility is a requirement for survivors.

"I am a person whose both breasts were removed as part of my treatment. I had bitter experiences and bad comments from health workers when I consulted hospitals other than TCC, which hurt me a lot. The special OPD is acceptable as long as there are staff who respect and understand us, so that I don't have to come to TCC even for minor complaints" These were the words of 52-year-old Panjami.

Health facilities other than TCC may behave in an indifferent manner to the survivors. This may be because of their decreased awareness regarding the same or because they are not used to seeing patients who underwent mastectomy frequently.

In short, most of them have expressed the need for a special setup for survivors where they can get advice about food, exercise, awareness about signs of recurrence, and even counselling facilities in addition to their routine check-ups and mammograms. They also expressed their need for health workers to spend more time for enquiring about their other difficulties also. They believe that they will get more support and respect in such a setting. Such facilities are available in the developed countries (Halpern et al., 2016) and guidelines for survivorship care has been formulated by experts in cancer care such as ASCO and NCCN.(Denlinger et al., 2018; Runowicz et al., 2016). Though our survivors have never heard of or experienced such a facility existing anywhere, they gave their views on their needs, which they would be glad to use if available.

4.3.1.2.6: Why not designate the survivors and ‘ambassadors?

We asked the survivors what their opinion was on sharing their experiences with other newly diagnosed patients.67-year-old survivor Naina, stated that *“Women who are newly diagnosed from my place call me. I give them support and tell them about the treatment and ask them to be brave. They told me that they felt relieved talking to me”*

Case 3: Lavanya, 52 years, and mother of two
“*An incident I remember is that, once during my follow up (nowadays I am brave enough to go for follow up alone), a man came up and asked me whether I was a bystander. I said that I am the patient and have come for follow up. He told me his wife who was newly diagnosed with breast cancer, was crying and inconsolable. He requested me to talk to her. I spoke to her calmly. She had a lot of apprehensions regarding treatment and cure. I answered them based on my experience. I told her to take me as an example and that she will also come out of this. I felt that she was much relieved. I was happy that I could do something for a cancer patient****”.***

Case 3 reveals that it is not the feeling from the point of view of the survivor, even the society wants the survivors to share their experiences as they feel that it will give moral support to their dear ones.

Another survivor said that *"I did not have a chance to speak with a survivor at the time of my treatment. Had it been so, I feel my treatment would have been much easier. I feel that sharing experiences can make life easier for those under treatment"*

44-year-old Uma, who was diagnosed in the third stage said that *"I have written my experiences in my blog in the internet, so that it may be useful for someone. I also regular write articles about my breast cancer experience, so that nobody suffers from a delayed diagnosis due to lack of awareness like me".*

Her words state that social media was effectively used as a means of creating awareness.

52-year-old Krithi, who was in the early stage and on regular follow-up said that *"I did not regrow my hair after treatment. I am now a very active and normal person. My hair will remind others of my disease and I want to be a role model and tell them that this disease is curable"*

The survivors are taking it as their responsibility to be a role model for others. They also confess the wrong path they followed, so that others don't make the same mistakes.

"I also made the mistake of taking some traditional medicine, for which I became allergic and suffered a lot". The 67-year-old mother, Naina says that she tells others to go for scientific treatment only and to ensure not to get trapped with unproven cancer treatment.

There are quacks who practice cancer treatment locally, which can be harmful and lead to disease advancement. These treatments are unscientific, and can be harmful to the health of the patient or lead to disease advancement, as precious time is lost. Survivors will be of help to share their experiences and create awareness about unscientific treatments.

The fact that survivors can go a long way in creating awareness is clear from the above statements. They can also help in early detection is surprising. The experience shared by a survivor states this;

53-year-old homemaker, Ujala also said that *"I am not a health worker, but I was surprised when one of my friends asked me to examine her breast lump. She told me that since I already had the disease, I will be knowing the feel of a cancer lump".* The women were finding it more comfortable to disclose their symptoms to a survivor, as she believes that she can help her in identifying whether her breast lump is cancerous.

Another survivor 54-year-old Valsala, said that*," I had suicidal thoughts several times during my treatment days. Only that I did not get the right opportunity. Around the same time, I also heard that one patient could not come to terms with her disease and committed suicide. I think a disease-free survivor can help in such situations, by speaking to such people, boosting their morale, and by being an example that the disease is curable"*

From the above statements it is clear that these survivors unknowingly were becoming real 'ambassadors' of the disease. They can contribute a lot to society in facilitating early detection, awareness creation, providing moral support during treatment, and alleviating the existing fear about the disease and its treatment. Literature also support the fact that these survivors can become breast cancer advocates, and spread the message that this disease is curable (Becker, 2015). They themselves agreed to the fact and were happy to become ambassadors and help others. They wanted to showcase them as role models so that other people don't fear the disease and understand the fact that timely and scientific treatments will lead to a complete cure. It was also noted that, patients were finding it more comfortable to approach the survivors for advice regarding further steps during the initial days of diagnosis. Hence, it is important that we increase awareness among survivors about the disease so that they disseminate the correct messages. In our study, it is noted that in spite of going through the entire journey, awareness regarding symptoms and risk factors of the disease was less among survivors.

4.4.2: In-depth interviews among survivors who are at present living with the disease

4.4.2.1: Introduction

In-depth interviews were also conducted among survivors who are at present living with the disease and taking treatment for the recurrence of the disease. An understanding of the various issues faced by survivors who are now having a recurrence or living with the disease is also important for understanding survivorship.

In-depth interviews were conducted among ten survivors who were at present having disease recurrence or progressed to stage four from their initial stage at diagnosis. They were aged between 50 and 68 years with an average age of 59.25. All were married and having children, and one was a widow. One survivor had college-level education, six had a secondary level, and three women had middle-level education. One was a manual labourer and the others were homemakers. The initial stage of diagnosis was stage 2 in four women, stage 3 in five women, and stage 4 in one. Six women had a recurrence of the disease in 2021, two in 2020, one in 2017, and one survivor was having the disease spread to bone immediately after diagnosis. All of them are currently undergoing treatment.

The interviews were guided by the interview checklist. The interviews were conducted during the follow-up/ treatment visits at the TCC as detailed in the methodology section. During the interview, the survivors were asked about their perceptions as to why the disease has come back, their financial burden of treatment for the second time, how the family was managing the crisis, and the challenges faced by them regarding their work due to their ailment, treatment, etc.

4.4.2.2: Findings

The following sections will explain the themes that emerged which were categorised during the analysis of the qualitative data. (All names in the narratives are not real)

4.4.2.2.1: “Why me??”

The survivors were asked her thoughts on why she got the disease a second time, though many who underwent treatment along with her were disease free.

“I know that the disease recurred because of my carelessness. I ignored my symptoms initially.”

“It was my fault. I delayed the initial consultation due to fear and financial constraints.”

These are the words of two women; 54-year-old Mrs. Devi and, 66 years old widow Mrs. Paru respectively. On thinking back, they are now realising that the disease has recurred because they did not get it diagnosed in the early stages. They recalled that they either failed to recognize symptoms or to consult a health care worker on time. They consider themselves guilty of delaying their visit to the doctor.

Even though few of them recognized that something was wrong, they had various reasons which prevented them from undergoing a medical consultation immediately.

A 53-year-old survivor Sakhi, mother of three recalls that *“I delayed initial consultation by almost three months as my daughter was having her degree examination.”*

“*When I noticed the lump, it was my daughter’s delivery time. I was always active in organizing cancer detection camps in our place. I understood the symptom, but still delayed consultation. Only if I had consulted earlier…….”* The words of 66-year-old Savi, who was diagnosed with stage 3 breast cancer and developed recurrence in 2021.

“*Even though I told my husband, he said that the lump will go away on its own. There was nobody else to take me to a doctor. There was a delay of 3 months”.* said a 50yr old survivor, Bhavni.

“My husband was in Gulf at that time. Though I disclosed it to my sister-in-law, she said it was normal. At that time, I was breastfeeding my child. My disease had

already spread to the bone, by the time I was diagnosed." said Sumira another 50-year-old survivor with two children

All of them agreed that early diagnosis would have prevented a recurrence. They either failed to recognize symptoms or had other issues related to self or their family which delayed the consultation. Daughter's delivery, marriage in the family, and children's exam were frequently quoted as causes of delay in literature (Kumar et al., 2019). This was seen in our study also. Husbands working away from home or decreased awareness among spouses have also led to delay in presentation. Studies also reported decreased awareness among spouses, and stated that their improved awareness about breast cancer is an important factor which determines wife's attitude and practices (Al-Musa et al., 2019). All these can result in late stages at diagnosis with high chances of recurrence.

Most of them said that though their initial consultation was delayed, they were vigilant and more careful during the second time as stated by a 66-year-old widow Paru, who developed disease recurrence while she was undergoing treatment.

"For me, the disease came back when I was undergoing radiotherapy. I recognized it and informed my doctor immediately, even though my family said that it may be just my feeling. I could do this because I was going to the hospital every day at that time."

The words of Rema, 63-year-old mother of four also reflect the same. *"I knew that the disease itself was so. It may come again. So, when I had severe back pain, I did not waste time consulting anywhere else, I came straight away to TCC." "I regularly read health magazines; hence I could recognize signs of recurrence"*

The awareness of symptoms among survivors and accessibility to a health facility enabled them to recognise the recurrence and take treatment immediately. They did not have to wait for the decision from the family.

Two of the survivors 63-year-old Rema and 66-year-old Savi stated that they had followed all instructions and did regular follow up, but still, the disease came back.

They feel that it was due to the nature of the disease called ‘cancer’. They did not delay their initial consultation too; hence they feel that it was not due to their fault.

“I took all medications and did regular follow up. I don’t think that the disease came back because of my fault. The disease itself is so”

“I took all treatments, followed all instructions of my doctor, but still the disease recurred. I don’t know why”

Loss of trust in the treatment and cure and acceptance of fate were reflected in their words.

Even while under regular follow-up, it is important to be aware of the warning signs of recurrence, so that early medical care can be sought. Most of them did not know about symptoms of recurrence as stated by a 53-year-old survivor, Sakhi who developed recurrence in the lungs.

“I did not recognize. I thought the disease will come back only in the breast area. I had cough, but thought it was due to an allergy. There was painting in the house in connection with my daughter’s marriage. I consulted doctors only when the cough did not subside after 3 months.”.

“My thinking was that the disease always comes back in the breast area. So, I regularly checked my breasts. I did not know about any other warning signs to look for” said a 68year old Kantha.

“Nobody told us about signs of recurrence. Though I felt something was wrong, I could consult a doctor only after two months due to the COVID crisis. There should be some alternative” said a 50-year-old, Bhavni diagnosed initially with stage 3 breast cancer.

From the above statements, we can understand that the women thought that breast cancer recurrence always occurred in the breast area. Hence, they concentrated on getting their breasts checked up and undergoing mammograms. They were not aware of the fact that the disease can spread to other organs like the lungs, liver, brain, and bone and that the symptoms might be different. All of them said that they were not told about the warning signs of recurrence during their follow up visits. They expressed their desire to be told about these warning signs during their follow-up visits. This will help in early medical consultation and initiation of treatment. Again, these point to the need for a survivor clinic that can give awareness about recurrence signs too, in addition to other needs specified above by the survivors. Facilities for follow-up clinics and alternate arrangements for consultation with health worker during crises situations like the COVID pandemic was also mentioned.

4.4.2.2.2: Work-related challenges

Those in whom the disease had recurred, had symptoms that hindered them from doing even their day-to-day activities. Many had reported that pain due to spread of cancer to bones and breathlessness due to disease affecting the lungs, tiredness, and sleeplessness as causes,

"Now I cannot do any work due to cough and breathlessness. Cannot sleep at night"- this was stated by Sakhi.

A 66-year-old Paru said *"I cannot do any work now. I was a manual labourer and wish I could continue my job as I have a loan to repay. I am a widow too. My daughter's husband also died recently. I am worried about family matters now more than my disease. My daughter has to work and look after me. I had taken a loan previously. I thought I will continue my job and repay it, but now that cancer has recurred, it is difficult to do my job.*

These words state that not only the symptoms, but worry about the family and financial issues were also affecting them. As stated above, due to the symptoms, they cannot work anymore which is leading to financial crisis. They have to depend on others for their treatment expenses.

All have stated that their family members were highly supportive and help them with household chores whenever needed. Even those who could do day-to-day activities were prevented by their family out of concern for them. This is reflected in the words of the following survivors.

"Though my husband and children don't allow it, I take pain medication and engage in gardening. I love to do that" said a 63-year-old Rema.

66-year-old mother, Savi said that *"My daughter-in-law helps me with household chores when I am tired after treatment"*

Another 63-year-old Rema, now undergoing treatment also said in the same lines *"I can do work, but my husband and children don't allow me to work due to concern for my health"*

Most of them are finding it difficult to do household chores due to their symptoms. They were having symptoms like breathlessness and pain which were hindering them from doing any work. The family also support them in their daily activities. Some wanted to work for financial reasons too.

4.4.2.2.3: Financial burden

The financial burden was a major concern during treatment. They were all undergoing treatment for the second time. Though they were all beneficiaries of Government treatment schemes, they had out-of-pocket expenses such as medicines, travel and so on. The words of Bhavni and Paru clearly state this.

"I am availing benefit from Government schemes for my treatment. But still, the transport expenses, weekly blood tests all have to be borne by me" said a Paru who is on chemotherapy now.

"I got help from treatment schemes even for the second time, though all medicines in the list were not covered. My husband cannot work anymore and the financial problem worries me."

For some, the amount available was already utilised during their first treatment. This is evident from the words of Rema, mother of four.

"I availed Karunya for the first treatment. Now for medicines, transport, tests etc. I have to bear the expense. I get cancer pension, but is very irregular"

Some could not claim the Government schemes as they do not come under the criteria for beneficiaries. Even though their financial position was good they were worried about other things like loneliness, helplessness etc.

"I am a taxpayer, hence did not get treatment schemes. My financial status is good. These are the words of a 68year old Kantha, who is under treatment now.

Most of them were able to avail government treatment schemes, however, all medicines are not covered by the schemes. Moreover, the expenses of the lab tests, travel etc have to be borne by the patients. They were finding it difficult as they were undergoing treatment for the second time. Only 40% of breast cancer patients with metastasis in Asian countries receive second line treatment through treatment schemes(Fan et al., 2015). There was a feeling of helplessness as those who were working after their first treatment also could not do so now due to health issues.

4.4.2.2.4: Concepts about treatment and cure

We wanted to know about what the survivors thought about cure and treatment of breast cancer when they got the disease for the second time. Most of them were finding it difficult in going through the whole treatment and tests again. After the first treatment, they believed that the disease was completely cured. These were evident from the words of the survivors.

"First time I had no tension. But now it is not the same. I have no courage or strength to bear the treatment" as quoted by a 63-year-old Rema.

"Though I fought the disease with courage the first time, I was completely depressed this time. I thought I was cured" said a 68yr old Kantha who was diagnosed with stage 2 disease and undergoing treatment now for recurrence.

Some were optimistic and faced the disease with courage even for the second time. They were finding their strength to face the disease from getting involved in spiritual beliefs like prayers and reading Holy books irrespective of their age.

"I believe in prayers. I read the holy bible. I am alive at least in this way because of the prayers of my loved ones". These were the words of 50-year-old Bhavni.

"I believe that I can still overcome. I spend my time in prayers "said Sumira another 50-year-old.

Religious beliefs and support structures were important coping strategies as per literature which was found in our survivors also

Some women expressed more concerns, in addition to getting cured.

" I have to take pain medicines. Now I fear that my kidney will be damaged due to this" The words of a 66-year-old mother (Savi).

"I am only sad that my daughters are busy and cannot come and stay with me. I was very happy when they stayed with me last week. I know that they have jobs and cannot come over frequently" said Kantha, a 68-year-old mother of two.

"My family has to spend money on my treatment. Nowadays I cannot do any household work also due to breathlessness." said Sakhi, another survivor who is on chemotherapy now.

These words clearly indicate that the worry of the survivors who have recurrence is not only about the treatment and financial issues. There were also other factors. These include adverse effects and complications following treatment, loneliness due to lack of presence of near and dear ones, and stress due to the feeling of being a burden to the family.

Two of the survivors were not aware of their present cancer status. One survivor came to know about having the disease for a second time after a long time when she went to a doctor for treatment of diabetes.

"They did not tell me about my condition. I came to know about it only recently when my physician told me. I feel that family should not hide it from us"

A 50yr old survivor Navya said *"I don't know about the extent of my disease and why I am taking treatment even now*"

"I don't know about my disease. Only my daughter knows", said Savi whose elder daughter was accompanying her for treatment.

Though the family members thought that the patient would not be able to bear it, and it was better to hide it from them, the patient's point of view was different. They wanted to know about their condition and why they were taking treatment at present. They wanted support from the family by their presence. Non-disclosure of the disease status was another concern raised by the survivors.

4.4.2.3: Summary

Having a cancer recurrence is an important care challenge for breast cancer survivors. It was important to understand the perceptions of these survivors to have a better understanding of their challenges and needs. The findings of our qualitative interviews highlight the complexity of their illness experience and the ways in which women visualised their cancer recurrence. The awareness regarding a delay in diagnosis leading to a recurrence is noted among survivors, though many have accepted it as a behaviour of the disease rather than their fault. All of these survivors were undergoing treatment now, though they have financial and family-related issues. Government treatment schemes are available for cancer treatment. 'Karunya Benevolent Fund' and 'Sukrutham' were the two cancer treatment schemes of the Government of Kerala. Presently, all the existing treatment schemes of the government of Kerala were merged with the Pradhan Mantri Jan Arogya Yojana (PMJAY) and named as 'Karunya Arogya Suraksha Padhathi' (KASP). Under this scheme, beneficiary families will get Rupees Five Lakhs per year for secondary and tertiary care hospitalization. Though the survivors benefitted from these schemes, many stated that they had to bear the travel expenses and expenses for medical tests from their pockets. Moreover, not all medicines are covered under this scheme. The symptoms of recurrence like pain, breathlessness, and decreased sleep have all affected their day-to-day activities and they are finding it difficult to do any work. Some have optimistic regarding cure, while, few said that they have lost the courage to fight. Awareness regarding the signs of recurrence was seen as minimal in our study except for those in the habit of reading health magazines. Support from the treatment system through health worker communication during their follow-up visits, is a good way to create awareness on warning signs. The survivor also expressed that they should not be kept in the dark and should be told about their disease condition. Spiritual beliefs and family support were mentioned by the survivors that helped them to cope with reality. This may help in solving problems like loneliness. These qualitative findings help in understanding survivorship through the perspective of the survivors.

4.5: Section 3: Policy analysis of Kerala state initiatives in breast cancer control and survivorship care

An analysis of policy documents with respect to the strategy, action plans, and health policy related to cancer control in the state, especially breast cancer control was done to fulfil the following objective:

4.5.1: Objective: To find out the policy associated with breast cancer control, with special reference to survivorship in the state of Kerala.

Inclusion criteria: Policy documents related to cancer control or health-related documents that discussed cancer control especially breast cancer in the Kerala context were included in the review.

Fifteen documents from websites and library were considered. After considering the inclusion criteria, finally, four documents were included in the review. The methodology regarding the selection of documents is detailed in the methodology section (Fig 3.4). The review was done as per the document review checklist prepared for the same (section 3.4.4)

Four documents were found to be related to policy regarding cancer control in Kerala. 1. Ten-Year Action Plan for Cancer Control in Kerala (Nair Krishnan M, 1988), 2. Draft Health Policy Kerala 2013 (Health Policy Kerala, 2013), 3. Kerala Cancer Control Strategy (2018-2030) (Kerala cancer control strategy, 2018) , 4. Health Policy Kerala (2019) (Health policy Kerala, 2019)

The documents were analysed keeping the objective in mind. The analysis was based on the policy document checklist to identify the key institutions and organizations involved in cancer/breast cancer prevention in the State. The documents were analysed to understand initiatives and measures adapted for breast cancer screening, diagnosis, follow-up and survivorship.

4.5.2: Document characteristics

All four documents included in the review discussed early detection of cancer, cancer prevention, and policies published in this regard. Three of the documents were published by the Department of Health and family welfare, Government of Kerala. The first document published in 1988, was for the State cancer control advisory board of Kerala which was constituted to coordinate the activities to achieve the objectives of the National Cancer Control Program for the state of Kerala. Second document regarding Health policy were published in 2013, the third document (Kerala cancer control strategy) was published in 2018. The fourth was the Health policy document were published in 2019. The objectives, governance, stake holders and the cancer control strategies described in the documents are detailed in Table 4.16 given below.

Table:4.16: Objectives, Governance, and cancer control strategies in the documents

S no.	Name of document (year)	Goals and objectives	Governance and Key institutions	Cancer control strategy
1.	Ten-Year Action Plan for Cancer Control in Kerala (1988)	Coordination of activities of the National Cancer Control Program in Kerala	Stata Cancer Control Advisory Board Chief Minister (Chairman) Health Minister (Vice Chairman) DHS, DME, RCC, Community participation	Cancer prevention activities using existing resources Early cancer detection and treatment Pain relief and rehabilitation Establishment of oncology units with treatment facility. State-wide tumour registry
2.	Draft Health Policy Kerala (2013)	Achieving targets set by the 12th five-year plan. Moving towards universal health coverage	Not mentioned	Decentralisation of cancer treatment from Tertiary care to District hospitals and General hospitals. Early cancer detection facilities through camps and screening programs. Anti-tobacco activities

Table 4.16 ctd.

S no.	Name of document (year)	Goals and objectives	Governance and Key institutions	Cancer control strategy
3.	Kerala Cancer Control Strategy (2018)	Reduce the burden of common cancers Improve the quality of life of cancer patients through Kerala Cancer Grid linked to Universal health coverage provide strategic direction for cancer control till 2030	State Cancer Control Board and District Cancer Control Committee Multi-stakeholder, intersectoral approach RCC, MCC, CCRC, Medical colleges, District hospitals, and Private sector hospitals will form part of the grid.	Establishment of Kerala Cancer Care Grid Cancer prevention Cancer literacy Early detection Referral pathway Palliative care Kerala State Cancer Registry Cancer-related research Financial protection to reduce out-of-pocket expenditure
4.	Health Policy Kerala (2019)	Strengthening the Primary Healthcare system Advancements in healthcare The public-friendly healthcare system	Not mentioned	Cancer prevention activities at the Primary level Early cancer detection facility Radiation/Chemotherapy facilities at District hospitals, in all districts without a medical college Enhancing the state cancer registry

4.5.3: Analysis of the documents

Analysis of the documents was done as per the checklist. We analysed the documents based on the common themes and categorising them regarding breast cancer control including early detection, the importance of cancer registry as a source of reliable cancer-related data, and survivorship care, especially breast cancer survivorship care plans. Discussions are described under the following headings:

4.5.3.1: Context of discussion on breast cancer control in the documents

The concept of early detection activities in the oral, breast, and cervix was discussed in all four documents. The document in 1988 proposes teaching the community, the method of breast self- examination as part of early detection activity in breast cancer control. In this document, cancer control activities were mentioned to be a part of the activities of the general healthcare delivery system. The document also mentions the need for dedicated early cancer detection centres at the district level, with exclusive staff and infrastructure. Health Policy documents in 2013 and 2019 also mention the importance of early detection of women cancers like breast and cervix. The 2019 health policy document also mentions the need for more research in the area of breast cancer. It also mentions a breast cancer control project, but no other details are given. The cancer control strategy document in 2018, recognised the absence of a comprehensive framework for cancer control in the state. It also gave importance to early detection and prompt treatment and sets a secondary target of more than 55% of breast, oral, and cervical cancer to be detected early. It mentions operational research for the feasibility of integrating breast awareness and clinical breast examination for early detection of breast cancer and suggests that the results from the Thiruvananthapuram Breast Cancer Screening study will provide valuable leads for this initiative and for breast cancer control in Kerala. The document also mentions the need for financial protection to reduce out-of-pocket expenditure in cancer treatment. This document also underlines the importance of research in the field of cancer.

4.4.3.2: Context of discussion on cancer registry in the documents

In the ten-year plan document (1988) there is mention of cancer surveillance and plans for establishing a state-wide tumour registry encompassing all medical colleges of the state and cancer treatment facilities like General Hospitals and other mentioned institutions. It mentions organisation of a limited number of population-based registries in chosen urban and rural areas. The need for the augmentation of the tumour registry facility in TCC at headquarters for supervising overall state-wide tumour registry operations is also mentioned. The policy document (2019) also mentions the plans for establishing a state cancer register, but it was not implemented.

The Kerala Cancer Control Strategy document mentions the lack of a state-wide registry. It states that presently there are only three PBCRs (Thiruvananthapuram, Kollam, and Malabar) and 13 HBCRs. The document emphasizes the strengthening of information systems through the establishment of PBCRs to cover the entire state through the creation of the Kerala State Cancer Registry (KSCR). This will help in assessing patterns and the burden of cancer and provide data on survival rates for major cancers. The utilization of this data for the formulation of better cancer control policies in the state is also seen discussed in the document. Expansion of the already functioning cancer registries in the Northern, Middle, and Southern Kerala to cover other nearby districts is recommended. To overcome the challenges in the functioning of the registry and completeness of data, it states the need to make cancer a notifiable disease in Kerala. The importance was emphasised by mentioning that similar legislations already exist in Karnataka, Punjab, and West Bengal. The document also mentions the need to link cancer patients' data using electronic health records and AADHAR to felicitate regular and proper monitoring.

4.5.3.3: Context of discussion on survivorship care in the documents

All four documents were searched for the word "survivorship care'. We found that the word "survivorship care" was mentioned once in the Kerala Cancer Control Strategy document of 2018.

"Establish Kerala Cancer Care Grid (KCCG) to ensure access to diagnosis, treatment, and survivorship care without delay" is mentioned in the section on 'Strengthening Health Care Delivery for Cancer' (section S3).

In the scope of services of KCCG, there is mention of follow-up care in the Basic Cancer Prevention Units (PHC/CHC/Taluk Hospital/Selected Private Sectors), though no details are given. In the action plan, there are no mentions of any detailed survivorship care plans to be implemented in the state in the document till 2030.

In the other three documents, there is no mention of the word ‘survivorship’ or any plans for long-term follow-up of cancer patients.

4.5.4: Summary

The ten-year action plan for cancer control in Kerala (1988) was the first document that provided the highly needed direction and design for cancer control activities in the state. With the changing situations and advent of emerging technologies for detection and treatment, it was needed to review the ongoing activities and redesign the plans. Following this, other health-related documents were also formulated, which mentioned cancer control and also provided a few directions. The Kerala Cancer Control Strategy which is the most recently released document on cancer control (2018), has precisely charted out directions for Kerala’s cancer control activities till 2030.

All four documents reviewed have given importance to the early detection of cancers of the oral cavity, breast, and cervix. Implementation of cancer control activities by utilising the existing infrastructure was recommended by all, while the 2018 document described in detail, cancer control activities through the establishment of the Kerala Cancer Grid and empowerment of the primary care facilities for early detection. Even the earliest document in 1988 realised the burden on doctors due to screening activities, and suggestions to train healthcare workers and volunteers and utilise them for screening were given. The documents realised the importance of a state-wide tumour or cancer registry in providing data on the cancer burden and survival rates. They also emphasized on the quality and completeness of registry data. In this regard, the 2018 document mentions that steps should be taken for legislation to make cancer a notifiable disease in Kerala and PBCRs should be expanded to include all districts of Kerala. Accordingly, Govt of Kerala has issued orders to make cancer a notifiable disease. (H&FWD, Kerala, 2021)

It was also noted that none of the documents mentioned any clear-cut plans for follow-up of cancer patients or survivorship care. The word “survivorship” itself was only used in one document (2018-2030) that too only once. This means that there is no policy or guidelines regarding survivorship care in the state of Kerala.

Early detection of oral, breast and cervical cancers by utilisation of the existing health care system by empowering them and suggestions for improving quality of cancer, bringing about legislation for making cancer a notifiable disease were given emphasis in the policy documents, while no policy on survivorship care for any type of cancers existed in the documents reviewed.

DISCUSSION

Chapter 5

Discussion

Breast cancer ranks first among all cancers, globally. The five-year survival for breast cancer varies around the world (Allemani, Matsuda, Carlo, et al., 2018), with 90% in developed countries (US and Australia) and 40% to 66% in developing countries like India (Leong et al., 2010; Sathwara, Bobdey, et al., 2017). Availability and utilisation of early detection facilities, improved awareness, advances in the treatment arena and increasing life span will result in swelling of the cohort of cancer survivors in the future (Institute of Medicine and National research council, 2006). After being diagnosed with breast cancer, women have to address the physical, social, medical, and emotional obligations of their life. In such instances, her self-esteem is challenged, because the women has to come to terms with her "new normal" life (Campbell-Enns and Woodgate, 2015). Her quality of life depends on the degree of transition from active treatment to survivorship care (post-treatment care). The survivor from the physician community who was the first to raise concerns of survivors, Dr. Mullan (Mullan, 1985), was part of the committee of the Institute of Medicine constituted to document the unmet needs of cancer survivors. This was later published as a book with the title *'From cancer patient to cancer survivor- lost in Transition'*. This is a classic work that describes the transition process based on Mullan's experience and it adds value as he is also a physician. This attracted many and the need for studying survivorship got recognition. Among the various recommendations, the committee suggested special studies on survivorship based on cancer registries(Institute of Medicine and National research council, 2006).

The establishment of surveillance through cancer registries contributed to policy formulation and monitoring of control activities. But, registries are spread unevenly across the globe, and are fewer in numbers in some of the densely populated countries and hence can provide data from only 21% of the world population

(Chatterjee et al., 2016). Only 47 countries of the world have cancer registries which cover 100%of their population, while, other registries across the globe show wide range of variations in population coverage (Allemani, Matsuda, Carlo, et al., 2018). In India, population coverage of registry is only 15%, as most registries are located in urban areas, while 68% of population live in rural areas. (Chatterjee et al., 2016). This is important as validity of global statistics depends on the population coverage and quality of data on cancer in each country (Sung et al., 2021). The National Cancer Registry Programme (NCRP) under the Indian Council of Medical Research (ICMR) has successfully collected data on cancer incidence, mortality, trends and patterns since 1981 through a network of HBCR and PBCR. (ICMR-NCDIR, 2021). Though 269 registries are registered under NCRP, only data from 96 registries could be included in the national reports due to poor quality and incomplete information(ICMR-NCDIR, 2021). As cancer is not a notifiable disease in India, there are major challenges in data collection, leading to lack of representativeness of data. Few states like Karnataka and recently Kerala(H&FWD, Kerala, 2021) have issued administrative notifications for the same(ICMR-NCDIR, 2020a).

According to NCRP, breast cancer is the highest reported cancer in the registry similar to that of rest of the world (Sung et al., 2021). In general the survivorship research on cancer patients were from the hospital settings by identifying the survivors either from registries or medical records (Binsha et al., 2020; F and Sc, 2016; Inhestern et al., 2017; Knaul et al., 2020).

The workshop conducted in 2019 by National Cancer Institute (NCI) identified several gaps in survivorship research and recommended longitudinal, longer term research (more than 5 years follow up) and effective utilisation of existing data for understanding survivorship (Gallicchio et al., 2021). Registry data can be used to evaluate improved outcomes from a range of research projects including survivorship (Banydeen et al., 2015)

HBCR provides accessible information on cancer patients, their treatment and results(ICMR-NCDIR, 2020a). There are studies based on registry, both hospital based and population based, which look at stages of disease, treatment factors, temporal trends in cancer, future predictions and survival (Mathew et al., 2016, 2019; Mathur et al., 2020). Around the world studies on various survivorship issues based on cancer registries were conducted in Hamburg, the Danish registry, Los Angeles SEER registry etc (Arora et al., 2007; Carlsen et al., 2013; Mehnert and Koch, 2008). The studies on survivorship with utilisation of registry data are very few in India (D'Souza et al., 2021; Kaur et al., 2018).

The present study is based on the HBCR for the year 2016 at a TCC in Northern Kerala. The study identified the patients who sought care for breast cancer in 2016 and the researcher followed up the survivors after six years in 2022 for the purpose of understanding their survivorship issues.

This study on the patients or survivors based on the registries does not go without any shortcoming. The problems such as lost to follow-up, non-traceable due to improper or non-updated address, non-availability of mortality related information and so on were posing difficulties for the researchers to recruit them for a study. This was similar to other studies (Chatterjee et al., 2016). However, the present study was successful, as the researcher was able to study 209 (47.8%) survivors during the year 2022, who were identified from the 2016 cancer registry with an original number of 437 after accounting for deceased and lost to follow-up due to varied reasons (not traceable, single visits for an opinion, who did part of their treatment at TCC and so on). This was a decent number after six years of follow-up in any study (response rate 47.8%) as it was higher than that of other studies based on registry conducted in Germany(33%) (Inhestern et al., 2017) and Norway (41%)(Vandraas et al., 2022). In a registry based study on adult cancer survivors in US, about half of those who were alive after five years were are lost to follow up from their primary treatment centres even after explaining the importance of undergoing follow up (Gill et al., 2018).

Unlike other types of cancers, the fact that breast cancer has an advantage of early detection, better treatment outcome and better survival (Miller et al., 2022) made the researcher to plan a study on the survivorship of the breast cancer patients in Northern Kerala. In turn, this will also help in formulating policies to improve survivorship with necessary interventions.

5.1: General characteristics of the study population

5.1.1: Sociodemographic profile of the cohort of breast cancer survivors

Mean age of the study participants was 53.8 years with 60% above 50 years of age. This was almost consistent with the mean age in other studies in Kerala(51yrs with 53% above fifty years)(Ali et al., 2008), and other parts of India (Chopra et al., 2014; Doval et al., 2020; Parameshwari et al., 2013). Other studies also show that disease peaks between 4th and 5th decade of life among Indian women (Malvia et al., 2017; Nigam et al., 2014), whereas it is 55 to 60 years in the Western countries (Agarwal et al., 2007; Anderson et al., 2007; Leong et al., 2010). Majority of the women in our study participants were from rural areas (72%) contrary to hospital based study from Northern India, where majority were from urban areas. (Sathwara, Balasubramaniam, et al., 2017). Though, studies show that there is a decreased risk of breast cancer in rural areas (Nagrani et al., 2014), the urban rural divide is minimal in life pattern in Kerala (Jayalekshmi et al., 2006). In our study more than half of the reporting patients were from the district where the TCC was located. The increased number of rural patients in our study is due to the rural location of TCC, which increased its accessibility as noticed in another Indian study(Sandhu et al., 2010). Regarding educational level three fifth of the study participants had above fifth standard education. This was similar to other Indian study(Sathwara, Balasubramaniam, et al., 2017).

5.1.2: Disease related factors

Majority had a microscopic diagnosis at registration, with Invasive duct carcinoma was the histopathology which is consistent with the HBCR 2021 report(ICMR-NCDIR, 2021). Majority were Estrogen and/or Progesterone receptor positive in our study which was similar to that seen in other India data (Gogia et al., 2018; Nair et al., 2018). Her 2 positivity in our study is higher than that seen in other Indian studies (Doval et al., 2015; Gogia et al., 2018). The reason might be that in the TCC, FISH* is performed for nearly all patients who had IHC reports for HER2 neu as 2+. In India, the high cost and nonavailability led to restricted use of these tests(Ghosh et al., 2014)

Regarding the stage of disease, it is to be noted that in the present study about 60% were in early stage which is consistent with other studies from Kerala (Lakshmanan et al., 2017; Mathew et al., 2019). More than 70% of them belonged to stages 2 and 3 was also observed in other studies from Kerala (Mathew et al., 2016).This is quite different from other parts of India where only 46% presented in early stages (Sathwara, Balasubramaniam, et al., 2017).

We analysed association between sociodemographic factors and stage of disease at presentation at TCC. It was found that stage of disease was significantly associated with educational status. This is in confirmation with other studies from India (Ali et al., 2008; Mathew et al., 2019; Sathwara, Balasubramaniam, et al., 2017).Studies reported that rural population presented to the health care worker in advanced stages of cancer (Sathwara, Balasubramaniam, et al., 2017), which is contrary to the findings of our study that the people who lived in rural areas presented in early stages. Easy access to the rurally located TCC may be the reason as stated in other studies (Nene et al., 2018). Our study found no association between stage at presentation and age of the woman (Pakseresht et al., 2014) or marital status(Buja et al., 2018) as reported in other studies.

In our study 68.4% completed their treatment and this was much higher than the treatment completion rate(56%) reported in a study in Rwanda (Natarajan et al., 2020). Study from central India shows 36.8% underwent either partial or no treatment which was slightly higher (31.6%) than our study(Nene et al., 2018). Again, in our study early-stage disease was significantly associated with treatment completion, and this was consistent with the findings of study from Rwanda(Natarajan et al., 2020).

*FISH-Fluorescent *in situ* hybridisation test

A study in Kumasi stated that traditional healers, decreased awareness about insurance coverage and Islamic faith were found to have incomplete treatment history.(Obrist et al., 2014).

Responses to open-ended question revealed that in our study intolerance to treatment, age, comorbidities, and alternative medicines (3.2%) were associated with partial or no treatment. There was no association between treatment completion and religion in our study. Also, it is of interest to note that 70.5% of those living in rural areas have completed treatment, however, association was not statistically significant. It is also proven in other studies that those staying closer to hospital completed the treatment (Natarajan et al., 2020), and the majority of our study participants were from nearby districts of TCC.

In phase 2, cross sectional survey was conducted among survivors who were traceable and under follow up in 2022.The following sections discuss about the results of the cross-sectional survey.

5.2: Long term and late physical effects due to treatment in breast cancer survivors

Published literature shows that the treatment of breast cancer itself has many immediate and long-term effects(Runowicz et al., 2016; Zucca et al., 2012). These health effects are varying during different phases of survivorship and few are found to reduce in time. In our study the most frequent issues were fatigue (30%), numbness/weakness of arms (28.8%), lymphoedema (26.8%), cognitive issues (25%), chemo induced menopause (45.5%) and mood changes (42.6%). Symptoms like fatigue and cognitive issues were reported in qualitative studies conducted among South Asian women.(Singh–Carlson et al., 2013). The prevalence of fatigue in our study was found to be similar to other studies (Bower et al., 2006; Kaur et al., 2018).The pain reported by survivors in our study was 20%,which was higher than in other studies(Jariwala and Kaur, 2021; Kaur et al., 2018). Prevalence of lymphoedema was also in confirmation with other studies (Deo et al., 2004).

Weight gain, though described in literature as a long term effect of using chemotherapy(30% to 60%) (Runowicz et al., 2016), is seen less among participants in our study. This may be related to the better awareness and interest in health promotion activities like exercise as evidenced from the qualitative findings.

5.3: Self assessed perceived work ability among breast cancer survivors

One of the aspects studied among survivors in our study is their self-assessed work ability. Effects of cancer on work ability may be related to the disease itself or treatment (Boelhouwer et al., 2021, 2022). Work ability in our study was assessed using the WAI index. Though, work ability index was used initially to assess the municipal workers in Finland,(Ilmarinen, 2009) presently, it is used in studies among various occupations(Adel et al., 2019; Anbazhagan et al., 2016; Soumyashree et al., 2018) and in cancer (Lindbohm et al., 2012; Vandraas et al., 2022). Work ability were studied in different studies at different periods of survivorship using different variations of Work Ability Index (Musti et al., 2018; Boelhouwer et al., 2022). Most of them used the single question short scale WAIS. In our study 81% had work ability score above eight in the short scale, with mean sore of 8.49. These findings were consistent with other studies on breast cancer survivors (Carlsen et al., 2013; Lindbohm et al., 2012). On the contrary, one study (Vandraas et al., 2022)reported a mean score of 6.3, much less than our study, with only 16% showing excellent work ability, which is in contrast to 37% in our study.

Being married (Musti et al., 2018) and being free of other comorbidities were found to be associated with good work ability (Lindbohm et al., 2012) which was in confirmation with our study findings.

Having undergone mastectomy was described as a cause of poor work ability (Musti et al., 2018).Though good work ability was seen in 90% of those who have undergone breast-conserving surgery (BCS) in our study, a statistically significant association could not be established. Most of the survivors do not know the consequences of each type of surgery and which option was best for them. Many a time they decide the choice on their own. As one survivor said" *At that time you take hasty decisions and don't even think about the life ahead. Now I regret a lot."*

The different types of surgery available and the favourable and adverse consequences of each, if discussed with patients in detail, with sufficient time for decision making will improve the situation. This was also addressed by survivors in another qualitative study conducted in Bangalore, India (Michelle S. Barthakur et al., 2016).

In our study being employed was associated with good work ability, which is in confirmation with the prospective cohort study, that associated employment with quality of life(Tamminga et al., 2020). Even those in our study who had quit their jobs, expressed their desire to work again, but their family does not allow them, out of concern for their health condition. One survivor mentioned that *"Going to work decreases my tension. I feel happy as I forget about my disease".* Another woman also stated that though her family does not allow, she did not like to sit idle, but to engage in gardening and other activities at home. Studies, even among those who were unemployed also show that physical activity is associated with good work ability(Hult et al., 2018). This shows how important work is to a survivor, whether it be household chores or paid job, as good work ability is associated with good productivity (Ho et al., 2018)

Studies reported that social support from colleagues is associated with good work ability (Lindbohm et al., 2012; Musti et al., 2018; Vandraas et al., 2022). Our qualitative interviews found that our survivors received help and support from coworker who helped them to continue in their jobs and this made them happy. Most of the treatment related side effects were related to reduced work ability in various studies, and our study also found that fatigue, pain and depression were significantly associated with decreased work ability in conformation with those studies.(Ho et al., 2018; Vandraas et al., 2022; Von Ah et al., 2018). Though cognition changes were associated with decreased work ability in studies(Vandraas et al., 2022), it was not found in our study. The prevalence of cognition issues was only 25% in our study compared to 40% in another study (Runowicz et al., 2016). In our study age at the time of survey was not associated with work ability, similar to other study(Ho et al., 2018)

Study by (Musti et al., 2018) found that a significant number of survivors had to make adjustments and modifications in their household chores and employment (Syse et al., 2008). Similarly in our study, about two fifth of survivors reported they were either slowing down their work or changing the way in which worked earlier. Further, qualitative findings describe the alternate adjustments done like changing to a washing machine for washing clothes, seeking help for doing strenuous household activity like drawing water from the well and some have even started 'working from home', instead of going to office. As per literature 15-30% reported physical disability (heavy lifting)in their work due to treatment.(Von Ah et al., 2018) as stated above.

Lymphoedema is associated with work ability(Vandraas et al., 2022) in other studies. Even our study found the association, though it was not statistically significant. Our qualitative findings too were suggestive of lymphoedema affecting their work ability. A survivor stated *"I had to leave my job and cannot do much household work too due to edema of arms. I am forced to decrease the speed of my work. I think I am now doing only 70% of the work I did previously."*

Treatment induced menopause was associated with reduced work ability in our study. Though studies on effects of menopausal symptoms on work ability was not found, bodily changes due to menopause was found to affect the work ability even in women who were not breast cancer patients (Boelhouwer et al., 2022). Moreover, it is known that treatment related menopause results in poor emotional functioning in younger survivors(Ganz et al., 1998)

The present study found that work ability is associated with marital status, comorbidities, disease free state, fatigue, pain, employment status, anxiety, depression, and treatment induced early menopause.

5.4: Depression among breast cancer survivors

There are various studies in India and across the globe on depression in cancer survivors assessed during varying periods of the cancer trajectory and using a variety of scales. The PHQ 7 is used for screening of depression in various diseases and cancer and is also recommended by ASCO for screening of depression in cancer patients.(Andersen et al., 2014)

The prevalence of depression ranges from 1 % to 56% depending upon the study population, type of scales and cutoff points used for assessment, and duration past treatment, while in Asian studies it ranged from 12.5% to 31% (Carreira et al., 2018; Zainal et al., 2013a). Anxiety and depression are often assessed together in many studies. The prevalence of depression in our participants was 9.6% as per scoring utilizing the PHQ 9 scale. This was in confirmation with the above studies. It was found that long-term effects of cancer treatment like fatigue was associated with depression in our study .This was in consistent with other studies (Ganz et al., 2021; Zainal et al., 2013a). Treatment-induced menopause and associated symptoms of hot flashes was associated with depression in studies(Ganz et al., 2021). Treatment induced menopause was found to have higher frequency of depression in our study, but it was not statistically significant. This reduced the sexual desire leading to depression (Carreira et al., 2018; Zainal et al., 2013a) . Mood changes which were also related to menopause was found to have significant association in our study. This is in consistent with the study which states that post-menopausal status is associated with depression (Thakur et al., 2021). Depression was associated with present disease status in our study. In other studies also it is seen that disease progression was associated with increased depression (Carreira et al., 2018; Tsaras et al., 2018). Higher level of anxiety was significantly associated with depression among survivors in our study and was also reported in a US based study (Deshields et al., 2006). Higher levels of depression was associated with poor work ability score in our study which was similar to a study conducted at Singapore. (Ho et al., 2018) . Depression was associated with lower educational status (Carreira et al., 2018; Tsaras et al., 2018; Zainal et al., 2013b) was not found associated in our study.

Factors associated with depressions found in other studies are unmarried status(Hassan et al., 2015), having children (Breidenbach et al., 2022), having pain(Vahdaninia et al., 2010), long-term effects of cancer treatment like lymphoedema, , hot flashes due to hormone therapy, cognitive issues and numbness or weakness of arms, having comorbidity(Breidenbach et al., 2022), mastectomy, age, and occupation(Zainal et al., 2013a). All of the factors mentioned above were not association with depression in our study.

In our study further analysis using binary logistic regression strongly emphasis the association of depression with work ability and anxiety.

5.5: Anxiety level among breast cancer survivors

Prevalence of anxiety in various studies were from 22% to 38%, as per the scale used and the time of analysis(Ganz et al., 2021; Hassan et al., 2015; Mehnert and Koch, 2008). The prevalence of anxiety among our study participants was 18.7% based on the scoring system of the GAD 7 scale. It was also noted that 81.3% of women had no anxiety.

In our study being married was associated with lower anxiety level than being unmarried or divorced which is also found in other studies (Srivastava et al., 2015; Tsaras et al., 2018).

Undergoing mastectomy as part of treatment was associated with increased anxiety in previous studies (Breidenbach et al., 2022), but no significant association was found in our study. This is because most of the women opted to remove their entire breast due to fear of recurrence, even when they were advised breast conserving surgery (Doval et al., 2020)

Young age, comorbidities, having children (Breidenbach et al., 2022; Mehnert and Koch, 2008), low level of education, stage of disease (Tsaras et al., 2018) were associated with anxiety even five to six years after treatment in various studies. There was no such association found between anxiety and the factors mentioned above, in our study. Though not directly associated, comorbidities like diabetes causing fatigue which prevented them from doing day to day activities were reported by our survivors in the open-ended questions.

In our study, disease recurrence among the survivor was associated with higher level of anxiety, and is in conformation with the study conducted in Germany (Breidenbach et al., 2022). The finding on increased symptom burden leading to decreased physical functioning found among survivors with recurrence, in our study was in confirmation with this study (Tsaras et al., 2018).

Fatigue, comorbidities and having children was associated with both anxiety and depression among cancer patients (Vahdaninia et al., 2010). In our study only fatigue was seen to be associated with both. Disease recurrence was also associated with both anxiety and depression in our study and is also reported in previous studies(Vahdaninia et al., 2010) In our study prevalence of anxiety was much more than depression. This is also in confirmation with other studies (Hassan et al., 2015; Srivastava et al., 2015).

To summarise, long term effects of cancer treatment like numbness and weakness of arms or legs, chemotherapy induced menopause, hormone therapy associated mood changes, present disease status, level of depression and self-assessed work ability were significantly associated with present levels of anxiety among the survivors in the present study.

The factors that contribute to better survivorship like improving work ability and dealing with depression and anxiety will help improve their quality of life (Tsaras et al., 2018).

5.6: Awareness about risk factors of breast cancer among survivors

Among survivors**,** 84.7% are aware that a past history of breast cancer is a risk factor for recurrence or a second cancer. Awareness regarding family history as a risk factor for breast cancer is seen in 56% which is consistent with review from India. Awareness regarding other factors like not having given birth was 22% in our study while among general population ranged from 1% to 88%. Awareness regarding obesity as a risk factor was very low and comparable to general population

(Baburajan et al., 2022; Somdatta and Baridalyne, 2008). Late onset menopause as a risk factor for breast cancer was not known to either survivors or general population. Only 13.4% of survivors knew that increasing age is a risk factor for breast cancer as opposed to 42% in general population. In the interviews our survivors have quoted that they have seen many young women with disease during their visits to the TC, and they no longer believe that cancer is a disease of old age. Regarding family history ,the awareness was more among survivors(56%) as opposed to 13.7% to 48% reported in other studies (A Gadgil et al., 2015; Gupta et al., 2015).Late menopause was known to 2.9% only as opposed to 37%. Sedentary life style or decreased physical activity as a risk factor was not known much to both the groups, but was a little higher among survivors(19.6% and 15%) (Gupta et al., 2015). Over all, the awareness about risk factors was less among survivors. Stress, food habits, no breast feeding, hormones and trauma were seen among causal attributions to breast cancer as response to open ended questions, which was consistent with studies among survivors. (Gonzalez et al., 2015; Kadhel et al., 2018) A review says that lifestyle and modifiable risk factors were less stated by survivors(Dumalaon-Canaria et al., 2014), while in our study one fourth of women had stated unhealthy food habits as the cause.

5.6.1: Awareness about signs and symptoms of breast cancer among survivors

It is seen that all women (100%) were aware of the fact that a lump in the breast may be a symptom of breast cancer. Studies among urban women in Delhi states that only 70% of the women were aware of this fact ,although this was the symptom known to maximum participants(Elshami et al., 2022; A Gadgil et al., 2015). A study conducted in Delhi stated that only five percentage were aware that a painless lump was a warning sign even among urban woman (Somdatta and Baridalyne, 2008). There were studies also from India. where a breast lump was not always recognised as a symptom of cancer (Baburajan et al., 2022; Somdatta and Baridalyne, 2008). The experience of a lump in the breast, which was later diagnosed as cancer, is the reason for improved awareness regarding lump as a symptom in our survivors. This is in conformation with a study in Karnataka among rural women, which proves that history of lump in self or family is found to be associated with improved awareness (Baburajan et al., 2022). Other symptoms of which the survivors were aware of in our study like retracted nipple(51.7%) and abnormal discharge from the nipple(55%), was found to be very less (7%)in other studies(Somdatta and Baridalyne, 2008). Awareness regarding many symptoms like change in nipple position, skin puckering, nipple rashes, skin colour changes, and sudden changes in breast size was very less in our study. Awareness regarding symptoms other than breast lump as a sign of cancer has to be created as part of facilitating early diagnosis (Michelle S. Barthakur et al., 2016). Though in general, higher level of awareness is reflected as better health seeking behaviour, it did not always result in women seeking a breast examination from a health care worker (A Gadgil et al., 2015), as many barriers were reported by our survivors which was beyond having awareness.

5.6.2: Awareness about breast self- examination among cancer survivors

It was noted that 90% our survivors did a self-breast examination, of whom 30% did almost every day and 88% was confident that they could detect a new change in their breast. In comparison, only 11% of our participants confessed as doing a self-examination before diagnosis and majority were not confident at all(72%) of detecting any change at that time, and is in confirmation with findings in Indian study conducted among rural women (Baburajan et al., 2022; Lakshmanan et al., 2017; Manir et al., 2017). The fact that after being diagnosed with cancer, majority performed self-breast examination was also in confirmation with a study conducted among breast cancer survivors in Poland (Krzywonos et al., 2014).

5.7: Barriers to heath seeking among breast cancer survivors

The most commonly reported barriers were “too scared to go and meet a doctor”, “too embarrassed to go to a doctor “and worry whether the doctor will find out that I have cancer”. “Embarrassment to see a doctor” reported in our study was in confirmation with another Indian study(Kumar et al., 2019), but was in contrast to a study conducted at UK. (Green et al., 2023). The differences in the cultures between the two countries are reflected here. The other findings were consistent with the Oman study(Al-Azri et al., 2021a)

In a study conducted at Oman among breast cancer patients 66% presented to the hospital within one month of symptoms, which was in confirmation with our study(Al-Azri et al., 2021b).

Painless lump as a barrier for delaying help seeking reported in our open ended question was also reported in other studies (Mehrotra and Yadav, 2022; Somdatta and Baridalyne, 2008). Postponing the visit to doctor fearing loss of wages of self or the accompanying person explained by our survivors in the present study is in conformation with other studies (Rajagopal, 2022). Non availability of a lady doctor in the locality was a barrier reported by our survivors, which led to delayed help seeking. Often women felt it embarrassing to have an examination or even to discuss about their breasts to a male doctor, because of the feeling of ‘shame’ associated with it (Rajagopal, 2022). The patriarchal society, has instilled in the woman’s mind, the belief, that body parts such as breasts, a symbol of sexuality should not be touched or seen by another male (Rajagopal, 2022). Factors such as family responsibility, stigma, attributing symptoms to other trivial conditions (Green et al., 2023), fear, embarrassment in visiting male doctor which were described in our open ended questions was also seen in another Indian study (Kumar et al., 2019).

Despite high literacy among our survivors, the present study revealed a poor level of awareness regarding breast self-examination and the symptoms of breast cancer as reported in previous study among survivors (Parameshwari et al., 2013).

5.8: Strengths and limitations

The study has various strengths. First of all, it used the cancer registry as a source of study subjects and hence it helped in identifying all the survivors who were registered in 2016 in the TCC. The TCC had a well-established cancer registry department recognized by ICMR. The catchment area of the TCC included the entire northern area of Kerala. Hence the subjects were also from these areas. The study design was a retrospective one, and hence data regarding sociodemographic factors, disease status at presentation, drop outs, deaths and so on could be collected by going back to the medical records. Though six years have passed, we could trace 209 (47.8%) of study participants which was a reasonable number. The in-depth interview helped to have a deeper insight into the survivorship issues of these women and the service provisions which they propose for improving survivorship outcome. The principal investigator who is very experienced in community work conducted all the data collection and interviews. Validated data collection tools were used in the study. The study used both quantitative and qualitative methods, which enriched our findings on survivorship.

Since it is a hospital-based registry, only the cases which will register at the TCC will be included, which is a limitation. Variables available in the registry alone were utilized. COVID period had restricted survivors from coming to the hospital. This is also a limitation. The greater proportion of survivors who were available for follow-up were disease-free. There is a possibility of potential bias associated with this, which can also be stated as a limitation of the study.

SUMMARY AND CONCLUSION

Chapter 6

Summary and conclusions

Breast cancer survivorship is a nascent subject. The present study focuses on post treatment survivorship of breast cancer patients after six years of registration and at TCC. The present study begins with description breast cancer survivors from the HBCR, and it reports that better education and awareness led to most women reporting to the TCC with early stages of breast cancer. Majority of the women were around 45 to 50 years of age, although women as early as 25 years were also noted. This suggests that there is a shift in the age of onset of breast cancer to younger age groups, which is a point of discussion in the USA and other developing worlds at present. Three fifth of women presented in the early stage of disease. The present study threw some light on the attitude to treatment as it reported that more than three fifth of women completed their prescribed treatment. It was also interesting to note that presentation in early stages was associated with completion of treatment as well. The rural location of the TCC has made it accessible to this population and acted as a factor for treatment completion. With advanced strategies for early detection and treatment, women live long beyond treatment. Treatment of breast cancer in itself is not without side effects, which are either psychosocial in nature or hindering productivity or causing reproductive-related symptoms or all of the above. About one fourth experienced health issues such as fatigue, lymphoedema, and early menopause in our study. Survivorship, may be related not only to living with above-stated problems post treatment, but also making the women dependent on others for their livelihood or performing their duties. This necessitated the study of survivorship and the need for addressing the problem of survivors. Present existing cancer care begins with diagnosis and ends with the completion of treatment. This narrow approach to the problem deprived the women of care for survivor-related problems which is a systematic lacuna in the care system.

The present study has opened up different aspects of survivorship and the factors contributing to it. Good work ability, an indicator of better survivorship was found in three fourth of our survivors, though one fourth reported poor work ability. Being single, having progressive disease, lack of job, depression, fatigue and pain were found to be predictors of poor work ability in our study. Our study findings also show that one tenth of the survivors as having depression and one fifth as having anxiety. This also indicates the effects of post treatment manifestations on the quality of life of survivors, even after six years of treatment. In this study, we tried to address survivorship in terms of work ability, depression, and anxiety as its three dimensions. Sociodemographic factors, type of treatment and post treatment long term issues were factors associated with work ability, anxiety and depression It was also found that the three were interrelated with some common associated factors. Fatigue and present disease status was associated with all the three. Marital status was associated with both work ability and anxiety. Mood changes due to treatment induced menopause was related to both depression and anxiety. Hence, it is seen that improvement of the three dimensions will enhance survivorship outcomes. It was also of interest that only one fifth of the survivors were aware about the risk factors and even less were aware about symptoms of breast cancer even after going through the entire trajectory. Survivors also endorsed the various barriers associated with delayed presentation in the initial phases.

In-depth interviews conducted among the survivors also opened up a multitude of issues faced by these women. Various themes like body image concerns, post-treatment sexual life, fear of recurrence, social exclusion, socioeconomic support, and service needs of the survivors evolved, which gave new insights into the meaning of survivorship as experienced by these women. From our qualitative findings, it was seen that survivors were unknowingly becoming ambassadors/ advocates, and can be effectively utilized in disseminating the message of curability and early detection of breast cancer. They themselves unknowingly were supporting their friends and fellow groups during their initial days of treatment. For this the awareness among the survivors are to be enhanced. The survivors have expressed their desire for more facilities and care during their follow up period such as provision for counselling, treatment for comorbidities, awareness about signs of recurrence, advice regarding healthy diet and exercise and so on. A review of policy documents did not show the existence of any plans for follow up care or survivorship care plans for breast cancer survivors.

The efforts made and resources spend on cancer care, will all go in vain if it does not address the post treatment issues of survivorship. Alleviating symptoms of menopause, providing employment opportunities, screening for anxiety and depression in the beginning and then at regular intervals, and providing counselling or medical support where ever necessary can alleviate most of the survivorship issues. There is a need for systematic intervention by creating and integrating survivorship related services with cancer care. Giving psychosocial support, and empowering survivors for self-support with productive activities will minimize the trauma caused by the treatment of cancer.

Recommendations

In our study, cancer registry was used to identify the cohort of breast cancer survivors who have completed six years of treatment. Cancer registry is usually used for epidemiological studies, time trend analysis, survival analysis and to study incidences and mortality. Registry data can be effectively utilised for survivorship studies in cancer. A follow up care plan for breast cancer survivors is lacking in the in our State or even nationally, though such plans are existing in western countries. Dedicated clinics for survivors will help in addressing the medical, psychosocial as well as rehabilitation related needs of the survivors. The medicines used by the survivors during follow up are not covered by the Government health schemes. Breast cancer patients have to continue hormonal treatment (Tamoxifen) for ten years and have to undergo yearly mammograms, and other tests aa part of follow up. This results in out-of-pocket expenditure to these women. Financial assistance for treatment during recurrence is limited. Including follow up assistance in the Government insurance schemes are to be considered to decrease their financial burden. Employment is found to increase work ability and decrease anxiety and depression in survivors. Means of empowering these women with appropriate rehabilitation measures will help in better survivorship outcomes. Survivors should be effectively used as ambassadors for moral support of newly diagnosed patients as well as spreading awareness about cure and early detection of breast cancer and breaking the myths about the disease. It is also important to increase awareness about breast cancer among spouses as well as health workers including AYUSH and other systems of medicine, which will enhance early detection and cure.

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A1 Publications

Breast Cancer Survivorship Experiences: Protocol for a Retrospective Cohort Study Based on Hospital Based Cancer Registry of a Tertiary Cancer Centre in Northern Kerala, India

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ABSTRACT

Background: With advancement in early detection and treatment, the number of breast cancer survivors are on the rise. Long term survivors have in addition to medical problems related to treatment, psychological distress and challenges related to body image, sexuality and stigma. The survivorship issues related to breast cancer are largely under studied in India.

Methods/Design: This is a retrospective cohort study of breast cancer survivors from 2016 Hospital-Based Cancer Registry (HBCR) of a Tertiary Cancer Centre (TCC). Baseline data will be collected from registry. Quantitative data on present status and issues of survivors will be done by a cross sectional survey. In depth interviews will be done to explore the challenges of survivors and lived experiences of the co- survivors. Documents about cancer will also be reviewed to find out existing guidelines on breast cancer control.

Discussion: Understanding survivorship experiences will help to improve their quality of life and guide health workers and caregivers in providing the much-required support and care in their journey throughout the disease.

Keywords: survivor, cancer registry, breast cancer, Kerala, India

1.Background

Globally, the most common cancer diagnosed is that of female breast (11.7%),and is responsible for one in six cancer deaths in women (Sung et al., 2021). In India ,there has been a significant increase in incidence of breast cancer across all Population Based Cancer Registry (PBCRs) ,especially in urban areas (Sathishkumar et al., 2021). Advances in diagnosis and treatment have increased the number of people living with cancer even in low and middle-income countries (Aziz, 2007). Five year net survival is increasing over the years with 90% in North America and Oceania and 40% to 66.1% in India (Allemani et al., 2018; Sathwara et al., 2017). Study in a cohort of breast cancer patients in Kerala ,showed a five ,10 and 15 year overall survival of 79% ,66% and 51% (Viral et al., 2021). Survival is higher in urban areas due to availability and accessibility to better cancer care (Sankaranarayanan et al., 2010). The increasing numbers have led to discussions about the challenges related to their physical,

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psychological, social wellbeing as well as their post treatment needs (Campbell-Enns & Woodgate, 2015). Unmet needs reported by breast cancer survivors were much more than others (Burg et al., 2015).

The term 'survivor' and challenges of survivorship was first given by Mullan, a physician and a cancer survivor, as he believed that the concept of 'cure from cancer' did not fully convey their long-term issues (Mullan, 1985). Though the term denotes a win over cancer ,many still suffer from symptoms either due to cancer or it's treatment, job issues and challenges of supportive care needs (Khan et al., 2012). Based on his views, a committee formed by Institute of Medicine recognised survivorship as a distinct phase of cancer care, to raise awareness on needs of survivors and to ensure care during the entire cancer continuum (National Research Council & Institute of Medicine, 2005). Cancer survivorship ,now defined as the experience of living with, through and beyond a diagnosis of cancer, begins from the time a patient enters treatment and continues throughout life incorporating their physical, psychological ,social and financial aspects which requires support and assistance from the beginning (Marzorati et al., 2017). Survivorship extends through "acute phase" that begins with diagnosis and active treatment , "extended phase" that begins when treatment has ended but treatment effects remain, and "permanent phase" when chances of recurrence is less ,but long term effects remain indefinitely (Mullan, 1985). A diagnosis of cancer equally affects the near ones, hence National Coalition for Cancer Survivorship included them also in the definition. Issues related to follow-up care, late effects of treatment, cancer recurrence, second cancers, and quality of life add to the survivorship experience (Marzorati et al., 2017).

Physical problems like fatigue (Meeske et al., 2007), lymphoedema (DiSipio et al., 2013), treatment induced menopause, osteoporosis , impaired fertility ,weight gain and physical inactivity (Howard-Anderson et al., 2012; Kaur et al., 2018), hinders them from returning to work . In a survey, arthralgia and anxiety were the most frequently reported health problem followed by depression, hot flashes, vaginal dryness, cognitive deficits, and arm swelling (P. V. Gadgil et al., 2015). Though psychological distress decreases over time ,studies show a prevalence of 38.4% and 22.2% of severe anxiety and depression even at 18 months of follow up (Vahdaninia et al., 2010). Depression was related to being single, less educated ,lower economic status, pain, and body image concerns (Zainal et al., 2013). In addition to symptoms related to illness or treatment (Dsouza et al., 2018), breast cancer survivors have issues related to body image after mastectomy , concerns over womanhood, sexual issues, and social stigma (Barthakur et al., 2017) related to guilt of being responsible for the disease and increasing fear of the disability and death (Nyblade et al., 2017). In those above 65 years, non-cancer related health issues may also be of concern (Gilbert et al., 2008). Supportive care needs of long-term survivors are less studied compared to their treatment related needs (Ktistaki et al., 2017).

Aspects like stronger bonding of relationships after diagnosis and positive attitude towards life are also described (Adorno et al., 2018). Not all women accepted being called 'survivor' as it masked many of the symptoms and distress which were ongoing even after treatment like the possibility of recurrence (Rees, 2018) or they disliked the public identity due to the disease (Kaiser, 2008). Fear of disease or treatment , mental stress on thoughts of incompleteness of body ,difficulty in mingling with other people and financial issues were reported (Dsouza et al., 2018).

Most survivors experienced changes in job status even five to ten years after diagnosis, barriers being personal and work related (van Maarschalkerweerd et al., 2020). Breast cancer survivors experienced low work ability than control groups due to low income, fatigue and poor support from supervisors (Carlsen et al., 2013).

Low level of awareness about symptoms was the major barrier to early diagnosis in India, even among urban women and self-examination was rarely practiced (A. Gadgil et al., 2015; Gangane et al., 2015; Kadam et al., 2016). Though breast lump was the most recognised symptom (Al-Azri et al., 2021), only 66% sought medical help within a month and reported barriers like feeling scared and worry over what doctor might find. With a patriarchal society existing in India, there may be other hindering factors (A. Gadgil et al., 2015). However , on comparison, survivors exhibited higher level of awareness and regularly performed self-breast examinations (Krzywonos et al., 2014; Loh & Chew, 2011).

Clinical trials, cohort studies, cancer registries, and national surveys were utilised for expanding survivorship research (Ayanian & Jacobsen, 2006). In India , registry data were utilised for understanding the incidence and patterns of cancer (Rajan et al., 2021), temporal and time trends , projections for the future (D'Souza et al., 2013) and survival analysis (Sathwara et al., 2017). Breast cancer research in India were largely on awareness, treatment, epidemiological trends, genetics with few on survival experiences like psycho oncological aspects ,stress, coping, quality of life, long term effects of treatment and included heterogenous population at varying periods of survivorship (Aziz, 2007; Barthakur et al., 2017; Dsouza et al., 2018; Rajendran et al., 2021). Studies from Kerala were mainly on psychosocial aspects among patients either undergoing or within six months to two years of treatment (Daniel et al., 2022; Purkayastha et al., 2017). There are no studies on long time survivor cohorts based on HBCR data from the state of Kerala. Research on experiences of survivors and caregivers can guide the health system in addressing their needs and social challenges (Knaul et al., 2020).

The objectives of the current study are:

Among breast cancer patients in the 2016 HBCR of a TCC

1. To study the socio-demographic aspects, stage at diagnosis, histological types and treatment availed by evaluating registry data.
2. A. To study the present status among survivors(a) who are disease free (b) living with disease (recurrence, residual disease or a second primary) B. To study the following from the survivors (a) perceived work ability (b) level of anxiety and depression (c) barriers to help seeking and (d) awareness level regarding breast cancer.
3. To explore experiences and factors related in case of survivors and lived experiences of caregivers in those who died.
4. To analyse policy documents associated with cancer control especially breast cancer in Kerala.

2. Methods/Design

2.1 Study design

This is a retrospective cohort study.Here eligible subjects are identified retrospectively, a cohort is composed and the investigator starts with the exposure and other variables at baseline and at follow-up and measures the outcome during the follow-up period (Euser et al., 2009; Ranganathan & Aggarwal, 2018). In this study, details of breast cancer patients registered in the TCC in 2016 will be taken from HBCR. These patients will be followed up and data collected to understand their present status and the issues faced during their journey.

The study has 4 phases

Phase 1

The data of all breast cancer patients registered in the TCC in 2016 as recorded in HBCR will be collected from hospital records utilizing the unique patient number (UHID) obtained from the registry department. The questions from HBCR core form of Indian Council of Medical Research (ICMR) will be used as baseline.

Phase 2

Cross sectional survey of breast cancer patients from 2016 HBCR will be conducted to know the present status of those who are currently disease free or living with disease recurrence or second primary and to understand the long-term medical issues, levels of anxiety, depression, perceived work ability, knowledge about the disease, and the barriers they faced during help seeking. They will be individually contacted or hospital records will be scrutinized for recent documentation of their condition. All those who are alive, contactable and consenting for the survey will be included in this phase.

The survey questionnaire will be prepared with questions to assess awareness about breast cancer and barriers faced during health seeking process by referring to breast module of the Breast Cancer Awareness Measure toolkit version 2 developed by Cancer Research UK (Linsell et al., 2010), long term effects of cancer treatment by referring from American Cancer Society breast cancer survivorship care guidelines (Runowicz et al., 2016), perceived work ability using Work Ability Index tool (Ilmarinen, 2007; Schouten et al., 2015) and the level of psychosocial distress (Andersen et al., 2014; Kroenke et al., 2001; Purkayastha et al., 2017; Spitzer et al., 2006). Tool will be prepared in English and translated to local language Malayalam. Linguistic validation will be done by forward and backward translation methodology. The questionnaire will be administered by the Principal Investigator (PI), either during their follow up visit or at any place convenient to the subject after obtaining consent.

Phase 3

This phase is to understand the experiences of those who are cured; the barriers and challenges of those have residual or recurrent disease and lived experiences of nearest kin of those who have died. In depth interviews using a check list, will be conducted among those women who are either survivors or the nearest kin of those who died. The outcome will give a deeper understanding of their trajectory through the disease.

Phase 4

Published government documents and details available from official online sites associated with cancer policy will be reviewed to understand the importance given to cancer and breast cancer in particular. The existing facilities and other government initiatives for early detection, treatment and follow up will be analysed.

2.2 Study setting

A TCC situated in northern Kerala will be the study setting for the registry-based data. HBCR, initiated in the TCC in 2010, was included under the network of National Cancer Registry Program (ICMR) in 2017.Data will be collected from patient records utilising the UHID.

The cross-sectional survey from survivors will be done either from the hospital during their follow up visits or in the community at any place convenient to them after getting informed consent. The TCC has patients from seven districts and the neighbouring states of Tamil Nadu, Karnataka and Mahe.

In-depth interviews from the survivors will be done in the community at any place and time convenient to the key informant.

2.3 Participants and sample size

The data of all 534 breast cancer patients registered in 2016 HBCR of TCC will be included in the study.

For the cross-sectional survey, each woman will be contacted to assess their present status or hospital records will be scrutinised for the latest documentation. The final sample size will be determined after taking into consideration those who are not contactable, those who do not consent and those who have died. Inclusion criteria are those who are alive either disease free, living with disease, having recurrence or second primary and give consent. Exclusion criteria are those who do not give consent, those who are not contactable and those who have died.

For key informant interview, sample will be selected purposively based on the survey and willingness. Care will be taken to collect data from a heterogenous group so as to include different situations. Data will be collected from survivors (1) who are disease free (2) living with the disease (3) nearest of kin of those who died. In each category, a sample size of five will be considered or until data reach saturation, no new information is contributed, and no new codes produced.

2.4 Variables and data sources

From the registry, data will be collected regarding age, sex, place, religion, mother tongue, marital status, date of registration, status at registration, date of first diagnosis and method, morphology, the laterality of lesion, clinical extend, stage at diagnosis, Performance Status (PS) at registration, type of treatment taken, date of completion of primary treatment, if no treatment is taken reasons for non-treatment, PS at six months of follow up, date of last visit and date of death if applicable.

In the cross-sectional survey, in addition to sociodemographic data, the variables include those regarding symptoms of long-term medical complications of treatment, perceived work ability, levels of anxiety and depression, barriers faced in the help seeking process, and awareness level about breast cancer.

For qualitative data, an interview checklist prepared by literature review and discussion with experts will be used to explore information to understand the experience of those who are cured; the barriers and challenges of those are living with the disease and lived experiences of caregiver of those who have died. The interviews will be conducted by the PI.

2.5 Limitations

We are including survivors from 2016 registry only. The facilities for treatment, access to treatment etc might be different from the present period. The women may have difficulty in recalling events as well. As our aim is to explore the experiences of subjects who have completed a significant period after their treatment and about whom little is known, it justifies our sample selection.

2.6 Plan for data analysis

Descriptive statistical methods will be used (frequencies, percentages, means, standard deviations depending on whether the variables are categorical or continuous). Binary logistic and multiple linear regression models will be constructed to identify significant predictors. Early (stage 1 and 2) vs. late (stage 3 and 4) stages of breast cancer will be further explored for challenges faced in diagnosis, treatment, and return to work challenges.

Thematic analysis will be used for qualitative data. Content analysis of relevant secondary data will be done.

2.7 Ethical considerations

The PI has obtained approval from the Institutional Ethics Committee of both institutions for conducting the study(1617/IRB-IEC/13/MCC/26-05-2021/2 and SCT/IEC/1711/AUGUST/2021). There are no expected harms to the subject due to data collection method. The only thing may be the discomfort of remembering a dear one who died due to breast cancer during interview for lived experiences of nearest of kin. The participant will have to spend 25 to 30 minutes for the cross-sectional survey and 30-40 minutes for the in-depth interview. They may also have difficulty in recalling past events. The data collections and interviews will be planned at any place convenient to the participant or during their routine follow up visit to the hospital. Care will be taken not to cause any difficulty or delay in their follow up consultation. No invasive procedures are involved in the study and therefore no adverse events are expected. Privacy, and confidentiality of the subjects will be ensured at all levels and PI will be responsible for safekeeping the data. Before data collection, PI will obtain an informed signed consent from the participants, after briefing on the study objectives, purpose, benefit, risks and voluntariness to decide participation. Time (not less than 15 minutes) will be provided to each participant to read and understand the consent form which will be in local language.

3. Discussion

Survivorship experiences measure how a patient treated for cancer, function and experience life. Issues and cancer related concerns of survivors five or more years beyond diagnosis were largely unrecognised till recently (Gilbert et al., 2008). Understanding their unique medical and psychosocial needs will help in developing resources that can assist not only patients but also guide caregivers, and health care providers in the various pathways of cancer survivorship.

With the increase in the number of breast cancer survivors, there is a need for survivorship programs even in developing countries (A. Gadgil et al., 2015). Research to understand their needs and challenges will help in formulating guidelines for establishing models which are culturally acceptable (Ayanian & Jacobsen, 2006) and for improving their quality of life (Gilbert et al., 2008).

The strength of this study is that it is the first long term survivor experience study from Kerala and includes survivors from six districts from Northern Kerala. We expect that this will give a better understanding about the concerns of survivors in this part of the globe.

Declarations

Conflict of interest: The authors declare that they have no conflict of interest.

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RESEARCH ARTICLE

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Work Ability, Anxiety, and Depression among Long-Term Breast Cancer Survivors of Northern Kerala, India; A Historical Cohort Study

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Abstract

Background: Increasing number of breast cancer cases, and improved survival due to advancements in early detection, and treatment resulted in an increase in women living beyond a cancer diagnosis. Survivors have to face long-term physical effects as well as psychosocial issues post-treatment. This study aims to study survivourship in terms of work ability, anxiety and depression. **Methods:** Retrospective cohort study on female breast cancer survivors from Hospital Based Cancer Registry (HBCR) of a Tertiary Cancer Centre (TCC). Data from 2016 (n=534) were collected from the medical records, and a follow-up survey (n=209) was conducted in 2022 to study their survivorship issues. **Results:** In 2022, the mean age of the cohort (n=209) was 55.45 ± 9.36. The mean work ability score was 40.7±5.73 (95% CI 39.92 to 41.48). In the multivariate binary logistic regression model, those who were married (OR 7.15, 95%CI 2.61 to 19.55), disease-free (OR 15.27, 95% CI 2.36 to 98.7), employed (OR 9.09, 95%CI 1.12 to 73.5), having no fatigue (OR 2.6, 95% CI 1.05 to 6.48), no pain (OR 3.11, 95% CI 1.16 to 8.35), and no depression (OR 6.58, 95% CI 1.82-23.8) were found to have optimal work ability. Anxiety (OR 4.93, 95% CI 1.76 to 13.76), and sub-optimal work ability (OR 4.22, 95% CI 1.39 to 12.77) were predictors of depression among survivors. Disease status and fatigue were associated with all three dimensions of survivorship in our study. **Conclusion:** Understanding survivorship will help improve health outcomes in this population. In our study, work ability, anxiety, depression, and their associated factors were found to be interrelated. Interventions in these areas can go a long way in improving breast cancer survivorship.

Keywords: Breast cancer- work ability- Kerala- survivor

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Introduction

Breast cancer is leading globally in 2020 with more than two million cases [1]. Advanced treatment and early detection have improved five-year survival, leading to an increasing number of individuals living beyond breast cancer treatment [2]. While treatment is one side of the coin, the other side is the post-treatment consequences experienced by the survivor [3]. The term 'survivorship' refers to the experience of living with, through and beyond, a cancer diagnosis and the person is known as a 'survivor' [4]. The term 'survivor' was first used by Dr Mullan in his article "Seasons of Survival; Reflections of a Physician with cancer", where he told the world that cancer survivors have common experiences which are specific to them, that are different from the general population [5]. In Asia, breast cancer is diagnosed at much younger ages than in Western countries [6], the registry data from South India also confirming the same [7]. Cases are diagnosed in the early stages in Kerala as opposed to other parts of India [8, 9]. Early diagnosis results in better survival. This, in turn, has resulted in an increasing number of young survivors living beyond treatment in that region. While the physician is more cautious about the immediate side effects of cancer treatment and signs of recurrence, the survivor is more concerned about the hindrances to day-to-day activities caused by post treatment lymphedema, fatigue, pain, hot flashes, and so on [10]. Survivorship research is gaining importance in the presently, as the difficulties and challenges faced by these women can no more be ignored [11].

Breast cancer treatment has a multimodality approach, which has medical as well as psychosocial long-term and late effects [3]. The survivor also have issues related to their social roles, return to work, body image concerns, and sexual functions [12]. Work ability, is an important factor affecting her return to work [13], financial status, mental happiness, social relations and productivity [14]. Due to young age at diagnosis, work ability, anxiety, and depression are described as challenges to breast cancer

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survivorship [13].

In survivorship research, participants are identified either from registry or from the hospital outpatient departments. Fewer studies have enrolled cohorts of survivors, and followed them longitudinally through the survivorship continuum. Studies on survivors based on registry are scarce, moreover studies on survivors of breast cancer are also few in India [15], and there are no such studies from Northern Kerala. Studies on work ability of breast cancer survivors are also few in Asia [13]. The aim of the study was to understand the work ability, anxiety and depression among breast cancer survivors from Northern Kerala and associated factors.

Materials and Methods

This is a retrospective cohort study on breast cancer survivors identified from the HBCR of 2016. The study was conducted in a Tertiary Cancer Centre (TCC) in Northern Kerala, which has a Hospital Based Cancer Registry (HBCR), containing data of all cancer patients who registered there in that particular year. The detailed protocol regarding the phases of the study, sample size, sample selection, variables, data source, and data collection methods are described elsewhere [16].

All female breast cancer patients registered in the TCC in 2016 (n=534) were included in the phase 1 of the study. From 2016 to 2022, the number of survivors who were lost to follow up (n=147), and those who succumbed to the disease(n=113) brought changes in the cohort size. All survivours diagnosed in 2016, who were traceable in 2022 and gave consent for the study were included in phase 2. those with a history of anxiety or depression or on treatment for the same were excluded. The final sample size was 209.

For Phase 1, data was collected from the HBCR. For Phase 2, a follow up survey was done by administering the questionnaire directly by the principal investigator, to the survivors after getting consent, during their follow up at TCC, taking time to explain the questions and clarifying doubts if any. Data collection was done in a separate room near OPD with adequate privacy.

The questionnaire consisted of sociodemographic details, questions related to long term and late health effects of treatment, present disease status, and scales for measuring work ability, depression and anxiety among survivors. Work ability, is the ability to perform work, as per demands of the job, in relation to his/ her health and mental resources. In this study, work ability is measured using the Work Ability Index (WAI) [17], a valid and well accepted tool for perceived work ability of individuals. It includes seven items, with scores ranging from 7-49 with further categorisation into poor (7-27), moderate (28-36), good (37-43), and excellent (44-49) [18]. The seven dimensions include current work ability compared to lifetime best, current work ability in relation to demands of the work, number of comorbidities, current work impairment due to the disease, absenteeism, own prognosis of work ability two years from now, and estimate of their mental resources. Linguistic validity was done by forward and backward translation methodology, and reliability by using internal consistency approach (Cronbach's alpha 0.8). For assessing anxiety and depression in this study, we used the GAD 7 and PHQ 9 scales respectively, which were recommended instruments for screening by American Society of Clinical Oncology [19, 20]. The responses were scored as "not at all" (score 0) to "nearly every day" (score 3). The total score was 0 to 21(GAD 7) and 0 to 27 (PHQ 9) [20, 21]. Cut-off points of 5, 10, and 15 represent mild, moderate, and severe levels in both scales. Validated, published Malayalam versions are used in this study [22]. Scores less than five almost always signified the absence of depression [23], hence, a cut-off point of five was used for further categorisation [24].

Data was analysed and categorical variables were given as frequencies and proportions, and continuous variables as mean and standard deviations. Bivariate analysis of categoric variables was performed by contingency tables and Chi square statistics or Fischer's exact test with significant alpha level taken as .05. Binary logistic regression was performed with the dichotomised work ability, anxiety, and depression scores as dependent variable. The most predictive model for each was formulated by purposeful selection of covariates with significant associations and through a process of model refitting and verifications.

The qualitative information from open ended question as to 'what the participants felt were their causes of anxiety' was analysed. The responses of participants were first coded deductively, and as they started showing a kind of pattern, they were converted to themes and listed. The study received approval from the Institutional Ethics Committee of the institution where the principal investigator is a research scholar (SCT/IEC/1711/AUGUST/2021), and Institutional Ethics committee of TCC where the study was conducted (1617/IRB-IEC/13/MCC/26-05-2021/2).

Results

The study participants registered in the TCC in 2016 was 534, from six districts of northern Kerala. The mean age of the cohort in 2016 was 53.8 ±12.1 (25 to 85 years). Two-fifths of the participants were less than 50 years of age. Three fourth were married and more than 60% were educated above fifth standard. Majority were home makers (85%). Post-menopausal women accounted to 67.6%. Sixty percentage presented in early stages.

The mean age of study participants in 2022 included in phase 2(n=209) was 55.45 ± 9.36, with majority (68.4%) 50 years and above. Employed women constituted 18.7%. As per disease status, 95.2% were presently disease free, and 4.8% (n=10) progressed to advanced stages. In comparison with 2016, nine women were widowed and one got divorced, seven women lost their job, while two started new jobs.

The long-term and late physical effects of cancer treatment as reported by the survivors ('yes' or 'no' responses) were collected (Table 1). Treatment induced menopause and mood changes following menopause were seen in nearly half of the women, followed by fatigue (30%).

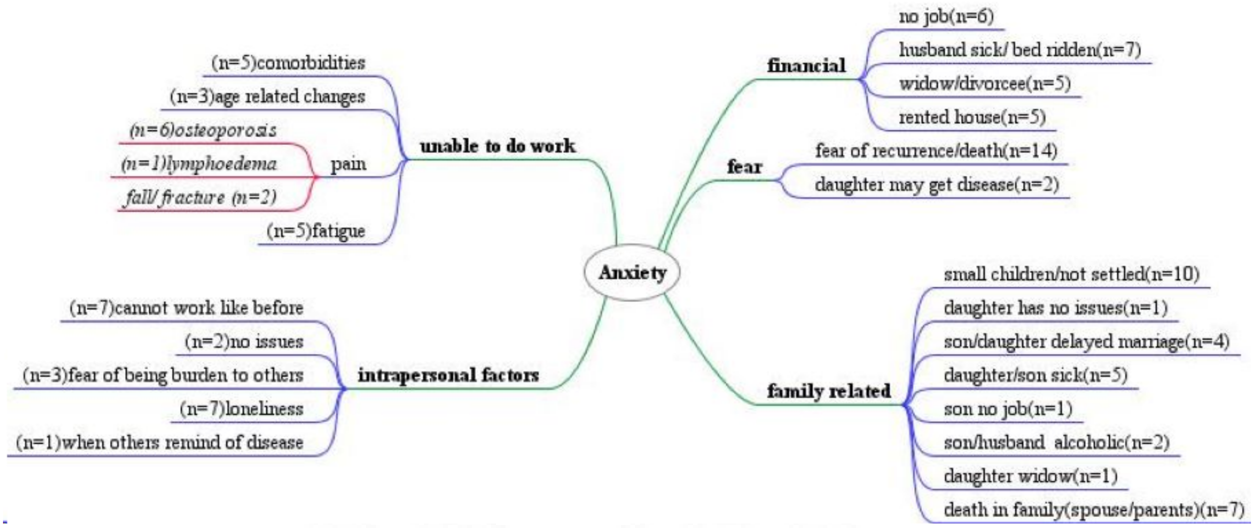

Figure 1. Causes of Anxiety among Long Term Breast Cancer Survivors as Reported in Responses to the Open-Ended Question "What do you think are the cause of your increased anxiety?"

Table 1. Long Term and Late Physical Effects of Treatment among Breast Cancer Survivors (n=209)

	n (%)
Fatigue	
Yes	64 (30.6)
No	145 (69.4)
Pain	
Yes	42 (20.1)
No	167 (79.9)
Lymphoedema	
Yes	58 (27.8)
No	151 (72.2)
Numbness /weakness of upper limb	
Yes	56 (26.8)
No	153 (73.2)
Cognition issues	
Yes	53 (25.4)
No	156 (74.6)
Osteoporosis related symptoms	
Yes	60 (28.7)
No	149 (71.3)
Weight gain	
Yes	23 (11.0)
No	186 (89.0)
Hot flushes	
Yes	40 (19.1)
No	169 (80.9)
Mood changes	
Yes	89 (42.6)
No	120 (57.4)
Menstrual changes	
Chemotherapy induced menopause	95 (45.5)
Others	114 (54.5)

The mean WAI score was 40.7±5.73 (95% CI, 39.92 to 41.48). Excellent work ability was seen in 37%, good in 45%, moderate in 13% and poor in 5% of women. For further analysis, this was categorized into 'sub optimal'(poor and moderate, score 7-36) and 'optimal'(good and excellent, score 37-49) [13]. About 82% of the survivors had 'optimal' and 18% had 'sub optimal' work ability. While 18.2% (n=38) of women reported no hindrance to daily work, 43.5% (n=91) of women had difficulty in carrying out their work due to some symptoms, 43% (n=90) had to either slow down their work or change their routine methods, 2.9% (n=6) could do only part time work, and 1% (n=2) were entirely unable to do any work. On bivariate analysis, sociodemographic factors like marital status and job, long-term effects of treatment like fatigue, pain, and treatment-induced menopause, present disease status, anxiety, and depression were factors significantly associated with work ability. Binary logistic regression was performed with the dichotomised work ability scores as dependent variable to understand the predictors. The indicator showing the correct fitness of the model was the Hosmer and Lemeshow test not being significant ($\chi2(7)$ =6.613, p=0.47). The independent variables contributing to the model include marital status, present disease status, employment, fatigue, pain, and depression. (Table 2) Being in a marital relationship, disease free status and being employed were significantly associated with optimal work ability and having pain, fatigue, and depression were associated with reduced work ability. Majority of women (n=199) were disease free, with only ten survivors living with the disease in 2022. The high OR values here are to be interpreted with caution.

The prevalence of depression among survivors was 9.6% (mild to moderate (9.1%), and severe (0.5%)). On bivariate analysis, depression was significantly associated with fatigue, menopause-associated mood changes, present disease status, present work ability, and anxiety. Binary logistic regression was performed with

Table 2. Summary of Binary Logistic Regression Analysis for Work Ability and Predictive Factors among Breast Cancer Survivors (n=209)

Variables	Workability		Unadjusted		Adjusted	
	Suboptimal (score7-36) n (%)	Optimal (score 37-49) n (%)	OR (95% CI)	p value	OR(95%CI)	p value
Marital status						
Married	23 (13.9)	143 (86.1)	3.33 (1.55-7.17)	<0.001*	7.15 (2.61-19.55)	<0.005*
Others	15 (34.9)	28 (65.1)			reference	
Disease status						
Disease free	31 (15.6)	168 (84.4)	12.65 (3.10-51.57)	0.003	15.27 (2.36-98.7)	<0.001*
With disease	7 (70)	3 (30)			reference	
Job						
Employed	1 (2.6)	38 (97.4)	10.57 (1.40-79.59)	0.005	9.09 (1.12-73.5)	0.003*
Homemaker	37 (21.8)	133 (78.2)			reference	
Fatigue						
Yes	20 (31.3)	44 (68.8)	3.21 (1.56-6.61)	0.001	reference	0.04*
No	18 (12.4)	127 (87.6)			2.6 ((1.05-6.48)	
Pain						
Yes	15 (35.7)	27 (64.3)	3.48 (1.61-7.51)	0.001	reference	0.02*
No	23 (13.8)	144 (86.2)			3.11 (1.16-8.35)	
Depression						
No depression	24 (12.7)	165 (87.3)	16.04 (5.63-45.74)	<0.001	6.58 (1.82-23.8)	0.004*
Depression	14 (70.0)	6 (30.0)			reference	
Menopausal Status						
Treatment induced menopause	11 (11.6)	84 (88.4)	2.37 (1.11-5.08)	0.02	-	-
Others	27 (23.7)	87 (76.3)				
Anxiety						
No anxiety	22 (12.9)	148 (87.1)	4.68 (2.15-10.20)	<0.001	-	-
Anxiety	16 (41.0)	23 (59.0)				

*, p value <0.05; OR, Odds ratio; CI, Confidence Interval

dichotomised depression scores “No depression” (score <5) and “depression” (score ≥5)) as the outcome. The correct fitness of the model was indicated by the Hosmer and Lemeshow test ($\chi2(6)$ =1.933, p=0.926). As per the model, sub optimal work ability, and anxiety were found to be the predictors of depression in survivours (Table 3).

The prevalence of anxiety among survivours was 18.6%; mild to moderate (18.1%), and severe (0.5%). It was further categorized to “No anxiety” (score<5), and “anxiety” (score≥5) [24]. On bivariate analysis, marital status, fatigue, mood changes, numbness or weakness of arms, work ability, present disease status, and depression were significantly associated with anxiety in our study (Table 4). It was found that 85%, women in a marital relationship and 86% of those without fatigue had no anxiety. Binary logistic regression was tried but a good fit model could not be obtained.

The themes which emerged on analysis of responses to open ended question include financial issues, family, intrapersonal factors, fear, and worry regarding the inability to do daily work (Figure 1). Each child node explained the respective parent node and their ultimate link to anxiety. No job for self, husband being bedridden or deceased, living in rented house all lead to financial issues and subsequent anxiety. The purpose was to substantiate the quantitative findings and not to explore the unknown. Findings show that women were worried more about other factors than the disease itself.

Dimensions of survivourship and associated factors as synthesis

We tried to analyse SURVIVORSHIP in the realm of its dimensions of work ability, anxiety and depression. Present disease status and fatigue were associated with all three. Mood changes due to treatment-induced premature menopause was associated with both anxiety and depression. Marital status was associated with work ability and anxiety. Work ability was associated with both anxiety and depression. As evidenced from the results, there were several factors which were common for the three dimensions of SURVIVORSHIP studied.

Table 3. Summary of Binary Logistic Regression Analysis for Variables Predicting Depression among Breast Cancer Survivors (n=209)

Variables	Category		Unadjusted		Adjusted	
	No depression (score<5)	Depression (score≥5)				p value
	n (%)	n (%)	OR (95% CI)	p value	OR (95%CI)	
Anxiety						
No anxiety	160 (94.1)	10 (5.9)	5.52 (2.11-14.43)		reference	
Anxiety	29 (74.4)	10 (25.6)		<.001*	4.93 (1.76-13.76)	0.002*
Present disease status						
Disease free	184 (92.5)	15 (7.5)	12.27 (3.19-47.16)	<.001*	-	-
With disease	5 (50.0)	5 (50.0)				
Present work ability						
Sub optimal	24 (63.2)	14 (36.8)	16.04 (5.63-45.74)	<.001*	4.22 (1.39-12.77)	0.01*
Optimal	165 (96.5)	6 (3.5)			reference	
Mood changes						
Yes	75 (84.3)	14 (15.7)	3.55 (1.31-9.64)	0.009*	-	-
No	114 (95.0)	6 (5.0)				
Fatigue						
Yes	51 (79.7)	13 (20.3)	5.03 (1.90-13.30)	<.001*	-	-
No	138 (95.2)	7 (4.8)				

*, p value <0.05; OR, Odds ratio; CI, Confidence Interval

Discussion

The five-year survival of breast cancer is increasing due to early detection, increased life span and advanced treatment, so are the number of women living long after treatment. Women have to accept their new normal life and move forward, amidst a spectrum of posttreatment effects, the price they have to pay for their survivorship [3, 25].

Table 4. Sociodemographic and Other Factors associated with Anxiety among Breast Cancer Survivors (n=209)

Variables	No Anxiety (score<5) n (%)	Anxiety (score≥5) n (%)	Chi-square p-value
Marital status			
Married	141 (84.9)	25 (15.1)	0.008*
Others	29 (67.4)	14 (32.6)	
Fatigue			
Yes	46 (71.9)	18 (28.1)	0.01*
No	124 (85.5)	21 (14.5)	
Mood changes			
Yes	63 (70.8)	26 (29.2)	0.007*
No	107 (89.2)	13 (10.8)	
Numbness/ weakness of arms			
Yes	37 (66.1)	19 (33.9)	<0.001*
No	133 (86.9)	20 (13.1)	
Work ability			
Sub optimal	22 (57.9)	16 (42.1)	<0.001*
Optimal	148 (86.5)	23 (13.5)	
Present disease status			
Disease free	167 (83.9)	32 (16.1)	<0.001*†
With disease	3 (30.0)	7 (70.0)	
Depression			
No Depression	160 (84.7)	291 (5.3)	0.002*
Depression	10 (50.0)	10 (50.0)	

†, Fischer's exact test; *, p value <0.05

This study had many challenges like lost to follow-up, non-traceability due to improper or non-updated address, non-availability of mortality related information, similar to other registry-based studies [26]. In our study, we could trace 47.8% (n=209) survivors during follow up, which was higher than other registry based studies in Germany [27] and Norway [28].

In the present study about 60% were in early stage which is consistent with other studies from Kerala [29, 8], and in contrast to Northern parts of India where only 46% presented in early stages [9].

In our study the most frequent post treatment long term physical effects reported were fatigue, numbness/ weakness of arms, lymphoedema, cognitive issues, premature menopause. and mood changes. The prevalence of fatigue and lymphoedema in our study was found to be similar to other studies [30, 15, 31]. Pain, as reported in our study was higher than in other studies [32, 15].

In our study 82% had optimal work ability as opposed to 64% in another study among breast cancer survivors, while those with poor workability was similar [13]. This may be due to the fact that, majority were in early stages and were below 50 years at diagnosis in our study. Being married [33], and being employed [34] were found to be associated with good work ability as in our study. Majority were married and the support from family may be the reason for good work ability in our study. Even among unemployed general population, physical activity was associated with good work ability [35]. This shows how important work is to a survivor, whether it be household chores or paid job, as good work ability is associated with good productivity, and better quality of life [13, 34].

Though fatigue affects functional capacity in breast cancer patients undergoing treatment [36], our study found that fatigue, pain and depression were significantly associated with decreased work ability among survivors too, which is in confirmation with other studies [13, 28, 37]. Cognition changes causing decreased work ability [28], was not found in our study, as cognition issues were reported by only one fourth of participants compared to other studies (40%) [3].

Studies report that a significant number of survivors had to make adjustments and modifications in both household chores and employment [33, 14]. Our study, also reports about two fifth of survivors either slowing down their work or changing the way in which they worked earlier or losing their job. Lymphoedema [28] was not significantly associated with work ability in our study. Treatment induced menopause was associated with reduced work ability in our study, menopause related bodily changes was reported to reduce work ability even in general population [38], and is described as cause of poor emotional functioning in younger survivors [39].

Mastectomy was associated with poor work ability [33]. Good work ability was seen in 90% of those with breast-conserving surgery (BCS) in our study also, though not statistically significant.

Various studies reported prevalence of depression ranging from 1% to 56% depending upon the study population, type of scales and post treatment duration [40, 41], consistent with our study. Fatigue was associated with depression in our study, in confirmation with other studies [42, 41]. Treatment-induced menopause and hot flashes were associated with depression in studies [42], but not found statistically significant in our study. Menopause induced mood changes had significant association with depression in our study as in other studies [43]. Depression and anxiety were associated with present disease status in our study. Other studies also reported that disease progression was associated with both [11, 40, 44]. Higher level of anxiety was associated with depression among survivors in our study as reported in a US based study [45]. Higher levels of depression was associated with poor work ability score in our study which was similar to a study conducted at Singapore [13].

Prevalence of anxiety in various studies were from 22% to 38% [42, 46, 47]. Prevalence of anxiety among our study participants (18.7%) was slightly less. In our study being married was associated with less anxiety, as in other studies [44]. Comorbidities like diabetes causing fatigue and hindering day to day activities led to anxiety as reported by survivors in the open-ended questions. (Figure 1) Increased symptom burden leading to decreased physical functioning found among survivors with recurrence, in our study was in confirmation with other study [44].

Fatigue, comorbidities and having children was associated with both anxiety and depression among cancer patients [48]. In our study only fatigue was associated with both. Having small children was also described as cause of anxiety by our survivors. Disease recurrence was associated with both anxiety and depression in our study, as reported in previous studies [48]. In our study prevalence of anxiety was much more than depression which also is in confirmation with other studies [46].

The post treatment period is a crucial period of transition from ‘cancer patient’ to a ‘survivor’ [41]. The factors that contribute to better survivorship like improving work ability by managing fatigue, depression and anxiety at the right time will improve their quality of life [44]. On synthesis, work ability, anxiety, depression, and the associated factors were found to be interrelated. Hence, they can be considered as the three dimensions of survivorship, and improving any one factor may result in better health outcomes.

Strength and limitations: Though this study may have limitations of a hospital- based study, that maximum survivors could be recruited can be mentioned as the strength of the study. There were only ten traceable survivors living with the disease in our study. This has influenced the OR as well, which has to be interpreted with caution.

Author Contribution Statement

Conceptualization: NAP, SK; Design: NAP, SK; Literature search: NAP; Data acquisition: NAP; Data analysis: NAP, SK; Manuscript preparation: NAP; Manuscript editing: NAP, SK; Manuscript review: SK..

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Ethics committee approval

Approval was obtained before starting the study from Institutional Ethics Committee of Malabar Cancer Centre (1617/IRB-IEC/13/MCC/26-05-2021/2) and, Sree Chitra Tirunal Institute for Medical Sciences and Technology

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Conflict of interest

The authors of this paper declare no conflict of interest.

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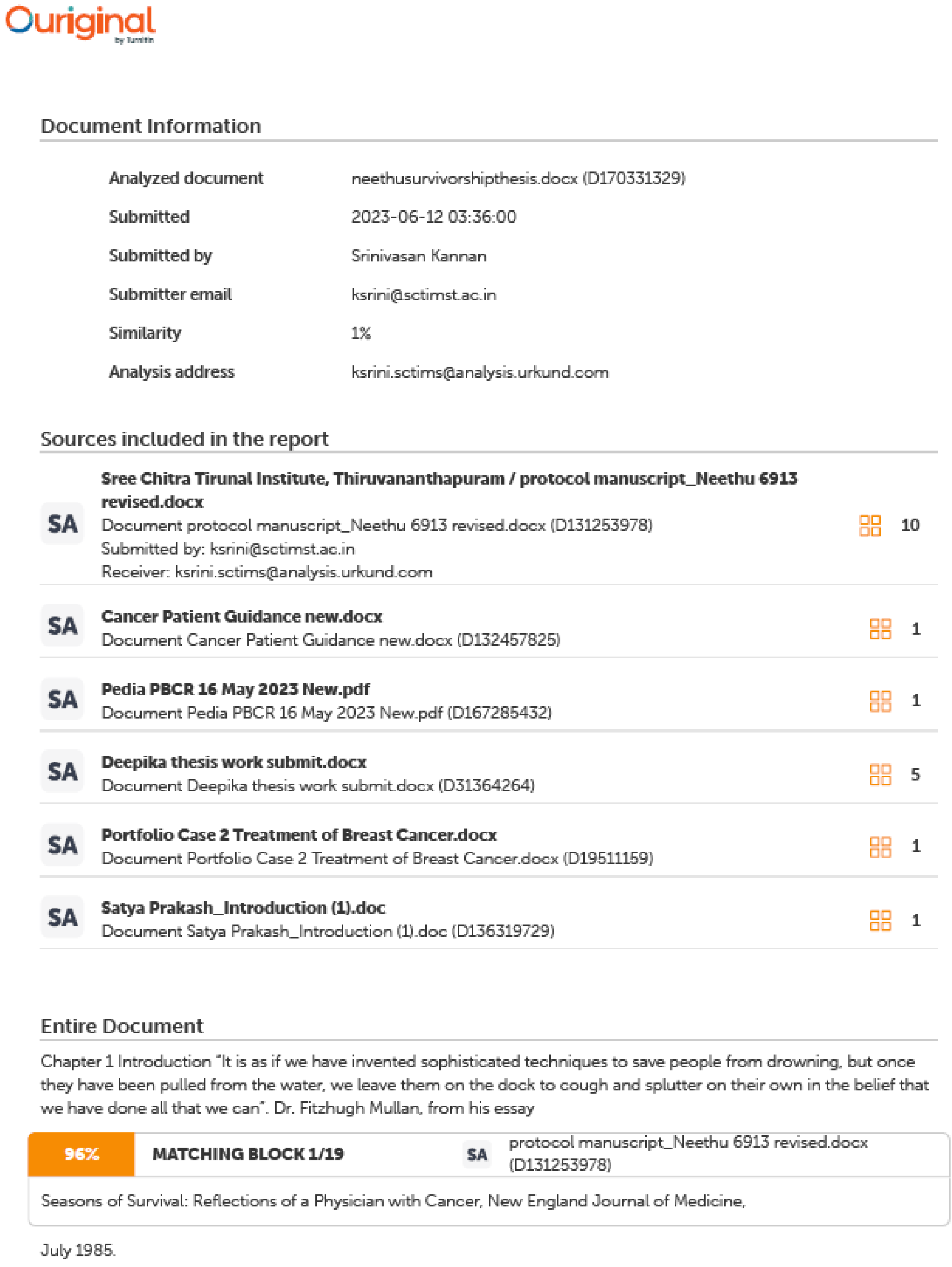

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Sources included in the report

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Chapter 1 Introduction "It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can". Dr. Fitzhugh Mullan, from his essay

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Seasons of Survival: Reflections of a Physician with Cancer, New England Journal of Medicine,

July 1985.

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Curriculum vitae

Name:	Dr Neethu A P
Designation	Lecturer
Department	Community Oncology
Institution	Malabar Cancer Centre, An autonomous institution under the Government of Kerala
E-mail	neetumcc@gmail.com
Mobile	9496048812
Date of Birth	15-09-1972
Qualifications	**MBBS** (Govt Medical College, Calicut, Kerala) (1992-1998) **MHSC** Public Health (School of health sciences, Annamalai University) (2011-2013) Currently pursuing **PhD** in public health from AMCHSS, SCTIMST, (2016 -)

Publications

1. Parambil NA, Kannan S. Breast Cancer Survivorship Experiences. *Social Science Protocols* 2022; 5: 1–10.
2. Parambil NA, Philip S, Tripathy JP, Philip PM, Duraisamy K, Balasubramanian S. Community engaged breast cancer screening program in Kannur District, Kerala, India: A ray of hope for early diagnosis and treatment. Indian J Cancer 2019; 56:222-7
3. Breast cancer screening in a rural area in Kannur district, Kerala, India; "The Kannapuram Model"- a community participatory approach **(**online only publication**:** Citation: 2020 Annual Meeting Official Proceedings, Volume XXI. Ann Surg Oncol (2020). https://doi.org/10.1245/s10434-020-08630-3

4. Parambil NA, Philip PM, Balasubramanian S, et al. Educational short film versus PowerPoint-based lecture in school tobacco awareness programs: Study from a tertiary cancer Centre, Kerala, India. *Indian Journal of Public Health* 2022; 66: 61.

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6. Philip PM, Parambil NA, Bhaskarapillai B, Balasubramanian S. Evaluation of a specially designed tobacco control program to reduce tobacco use among school children in Kerala. Asian Pac J Cancer Prev. 2013;14(6):3455-9. doi: 10.7314/apjcp.2013.14.6.3455. PMID: 23886127.
7. Philip PM, Nayak P, Philip S, Parambil NA, Duraisamy K, Balasubramanian S. Population-based cancer screening through community participation: Outcome of a district-wide oral cancer screening program from rural Kannur, Kerala, India. South Asian J Cancer. 2018 Oct-Dec;7(4):244-248. doi: 10.4103/sajc.sajc_104_17. PMID: 30430093; PMCID: PMC6190395.

Conferences and presentations:

1. Underwent training in cervical cancer screening by VIA/VILI and colposcopy in the colposcopy training centre at ISO and Govt Kasturba Gandhi Hospital for women and children, Chennai from 25/3/14 to 1/04/2014.

2. Participated in the GLOBAL CANCER SUMMIT2015 at Bangalore and made an oral presentation on “Effectiveness of symptom-based mass screening approach in early detection of breast cancer in selected 48 Panchayats of Kannur district in Northern Kerala”

3. Participated in the 61st annual National Conference of Indian Public Health Association (IPHACON 2017) at AIIMS, Jodhpur, and presented a poster on “Profile of Fine Needle Aspiration Cytology in the evaluation of breast lump detected in a cancer screening project in Kannur, North Kerala 2013-14”

4. Participated in the Scientific Symposium-Frontiers in Epidemiology at Mumbai (2017) and presented a poster on “MUNNETTAM-A novel movement in school tobacco awareness”

5. Participated in Indian Cancer Congress (ICC 2017) and presented a poster on “Educational short film versus conventional power point-based lectures in school tobacco awareness programs-study from a Tertiary Cancer Centre”

6. Participated in the 62nd annual National conference of the Indian Public Health Association (IPHACON 2018) at King George Medical College, Lucknow, and presented a poster on “Health literacy for all” –a comprehensive community empowerment program under Sansad Adarsh Gram Yojana, Kannur, India

7. Participated in the 64th annual National Conference of Indian Public Health Association IPHACON 2020 at AIIMS, New Delhi, and presented a poster on “Effectiveness of a structured awareness program in improving knowledge about cancer among women in rural Kannur, Kerala”

8. Attended the 21st Annual Meeting of the American Society of breast surgeons (AsBrs 2020) in Las Vegas on a virtual platform and presented an e-posted on “Breast cancer screening in a rural area in Kannur district, Kerala, India; “The Kannapuram Model”- a community participatory approach”

9. Attended International e-conclave on tobacco cessation 2021 in July 2021

10. Attended Global Cancer Summit 2022, on a virtual platform and presented a paper on “Demographic, tumour and treatment characteristics of female breast cancer patients in a tertiary cancer centre in Kerala on May 22nd.

11. Attended the 5th Amrita International Public Health Conference (AMRITACON 2022) and presented a paper on “Perceived work ability among breast cancer survivours diagnosed in 2016 and associated factors- a cross sectional study from a tertiary cancer centre in December 2022.

12.Active involvement in implementation and training programs of the District Cancer Control Program in Kannur, Kasargode, Wayanad, Kozhikode and Malappuram.

13. Technical support and training in the implementation and functioning of Early cancer detection centres at Cherukunnu, Neeleswaram, Ottappalam, Edavanna Govt. health centers and centres at Alakkode, Chittarikkal and Thomapuram under Charitable institutions. These centres were established for decentralized cancer control activities

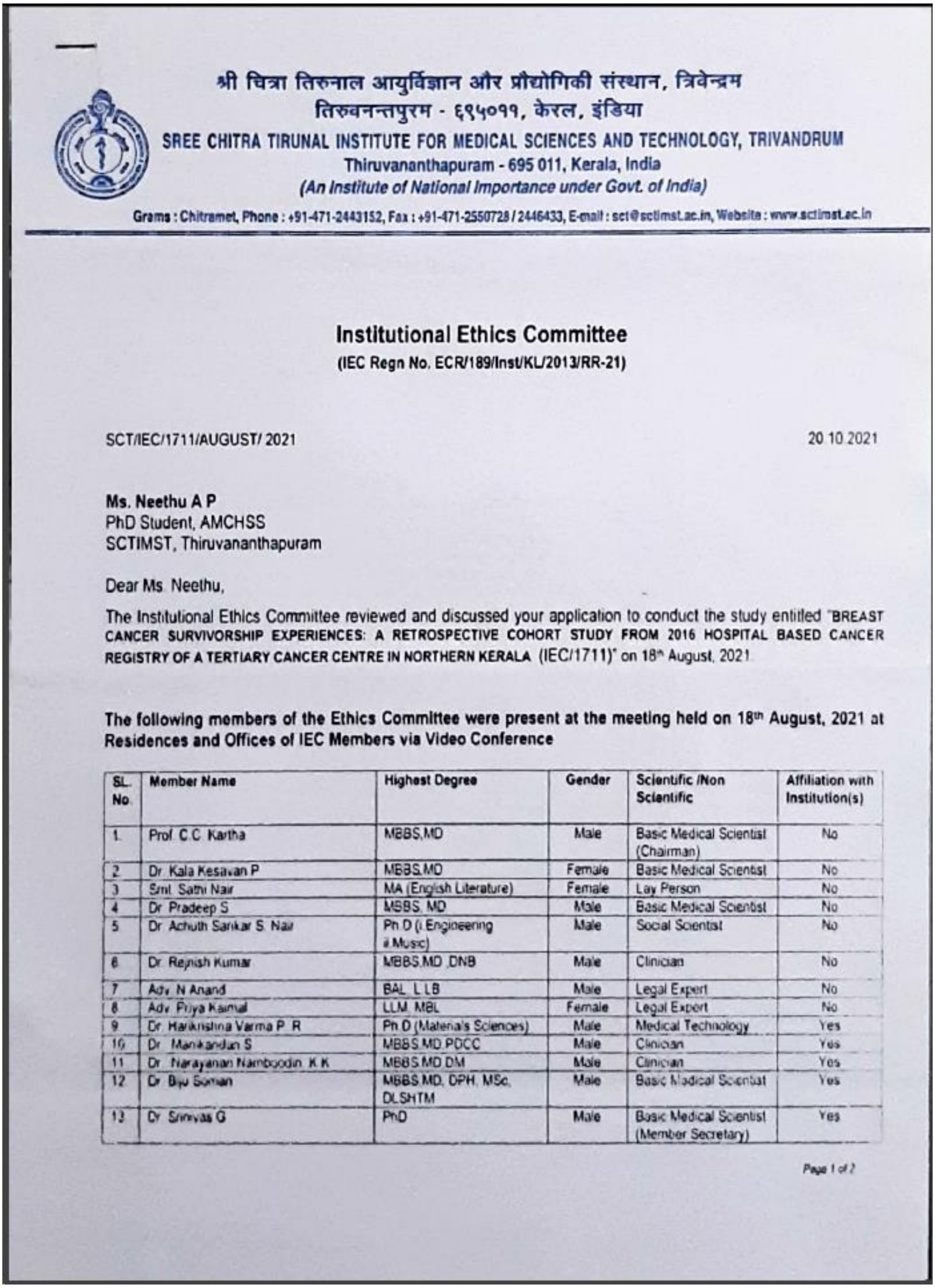
14. Ex Officio board member of Kannur District Cancer Control Consortium an initiative of MCC with the aim of cancer control through community participation Clinical and community activities

Joined Malabar Cancer Centre in 2003 and presently working as a lecturer in the Department of Community Oncology. The main activities of the Department include organizing and conducting cancer screening camps, cancer awareness programs, training programs for health workers in cancer control, and community-based research activities.

1. Awareness programs a. Cancer awareness campaign: cancer awareness classes for the general public and health b. Tobacco awareness campaign at schools: anti-tobacco awareness classes using audio-visual aids c. Exhibitions and observation of cancer-related health days: d. Training and workshops: Training in tobacco control and cancer screening for health workers and volunteers. e. Awareness-generating public competitions: f. Quarterly newsletter NETHI on tobacco awareness for school children g. publication of IEC materials for awareness generation h. short film for tobacco awareness “U-Turn”.

2. Screening camps a. Early breast cancer screening camps: b. Survey-based screening camps c. Tribal community cancer program d. Risk group screening camps

A4 Ethical clearance from IEC, SCTIMST, Thiruvananthapuram



श्री चित्रा तिरुनाल आयुर्विज्ञान और प्रौद्योगिकी संस्थान, त्रिवेन्द्रम
तिरुवनन्तपुरम - ६९५०११, केरल, इंडिया
SREE CHITRA TIRUNAL INSTITUTE FOR MEDICAL SCIENCES AND TECHNOLOGY, TRIVANDRUM
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Institutional Ethics Committee

(IEC Regn No. ECR/189/Inst/KL/2013/RR-21)

SCT/IEC/1711/AUGUST/ 2021

20.10.2021

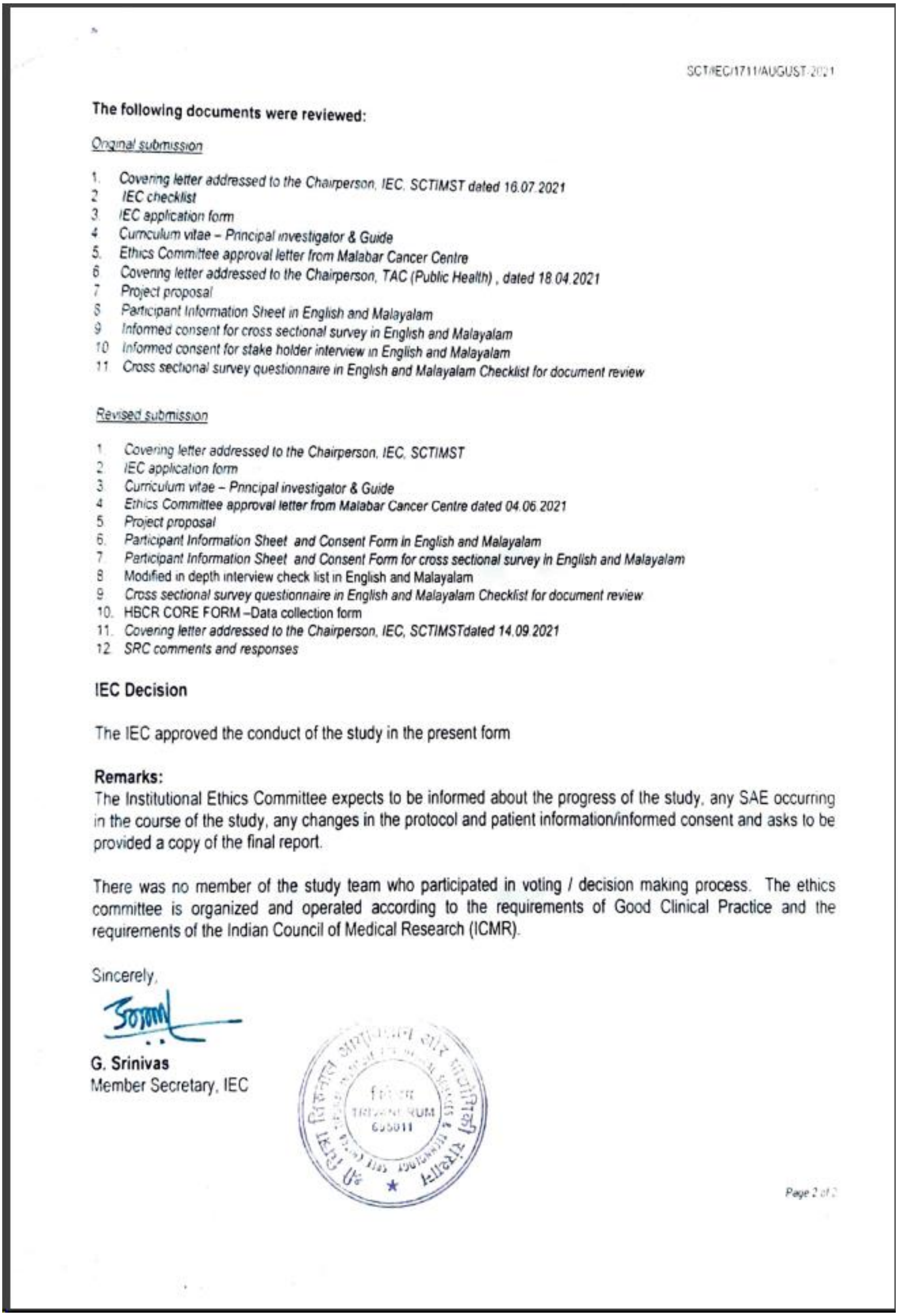
Ms. Neethu A P
PhD Student, AMCHSS
SCTIMST, Thiruvananthapuram

Dear Ms. Neethu,

The Institutional Ethics Committee reviewed and discussed your application to conduct the study entitled "BREAST CANCER SURVIVORSHIP EXPERIENCES: A RETROSPECTIVE COHORT STUDY FROM 2016 HOSPITAL BASED CANCER REGISTRY OF A TERTIARY CANCER CENTRE IN NORTHERN KERALA (IEC/1711)" on 18th August, 2021.

The following members of the Ethics Committee were present at the meeting held on 18th August, 2021 at Residences and Offices of IEC Members via Video Conference

SL. No.	Member Name	Highest Degree	Gender	Scientific /Non Scientific	Affiliation with Institution(s)
1.	Prof. C.C. Kartha	MBBS,MD	Male	Basic Medical Scientist (Chairman)	No
2	Dr. Kala Kesavan P	MBBS,MD	Female	Basic Medical Scientist	No
3	Smt. Sathi Nair	MA (English Literature)	Female	Lay Person	No
4	Dr. Pradeep S	MBBS, MD	Male	Basic Medical Scientist	No
5	Dr. Achuth Sankar S. Nair	Ph.D (i. Engineering ii.Music)	Male	Social Scientist	No
6	Dr. Rejnish Kumar	MBBS,MD ,DNB	Male	Clinician	No
7	Adv. N Anand	BAL, LLB	Male	Legal Expert	No
8	Adv. Priya Kaimal	LLM, MBL	Female	Legal Expert	No
9	Dr. Harikrishna Varma P. R	Ph.D (Materials Sciences)	Male	Medical Technology	Yes
10	Dr. Manikandan S	MBBS,MD,PDCC	Male	Clinician	Yes
11	Dr. Narayanan Namboodiri. K.K	MBBS,MD,DM	Male	Clinician	Yes
12	Dr. Biju Soman	MBBS,MD, DPH, MSc, DLSHTM	Male	Basic Medical Scientist	Yes
13	Dr. Srinivas G	PhD	Male	Basic Medical Scientist (Member Secretary)	Yes



The following documents were reviewed:

Original submission

1. Covering letter addressed to the Chairperson, IEC, SCTIMST dated 16.07.2021
2. IEC checklist
3. IEC application form
4. Curriculum vitae – Principal investigator & Guide
5. Ethics Committee approval letter from Malabar Cancer Centre
6. Covering letter addressed to the Chairperson, TAC (Public Health) , dated 18.04.2021
7. Project proposal
8. Participant Information Sheet in English and Malayalam
9. Informed consent for cross sectional survey in English and Malayalam
10. Informed consent for stake holder interview in English and Malayalam
11. Cross sectional survey questionnaire in English and Malayalam Checklist for document review

Revised submission

1. Covering letter addressed to the Chairperson, IEC, SCTIMST
2. IEC application form
3. Curriculum vitae – Principal investigator & Guide
4. Ethics Committee approval letter from Malabar Cancer Centre dated 04.06.2021
5. Project proposal
6. Participant Information Sheet and Consent Form in English and Malayalam
7. Participant Information Sheet and Consent Form for cross sectional survey in English and Malayalam
8. Modified in depth interview check list in English and Malayalam
9. Cross sectional survey questionnaire in English and Malayalam Checklist for document review
10. HBCR CORE FORM –Data collection form
11. Covering letter addressed to the Chairperson, IEC, SCTIMSTdated 14.09.2021
12. SRC comments and responses

IEC Decision

The IEC approved the conduct of the study in the present form

Remarks:

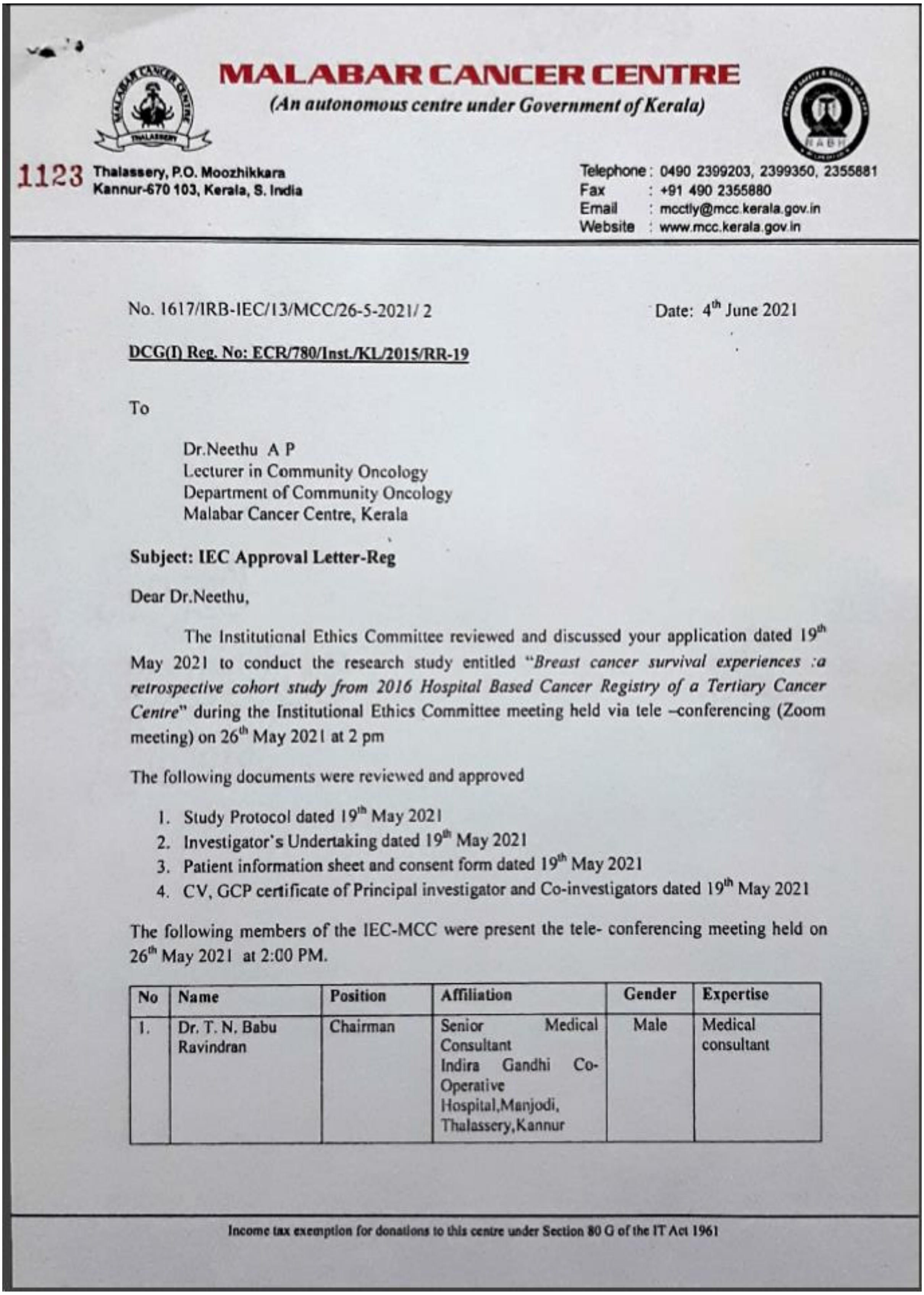
The Institutional Ethics Committee expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

There was no member of the study team who participated in voting / decision making process. The ethics committee is organized and operated according to the requirements of Good Clinical Practice and the requirements of the Indian Council of Medical Research (ICMR).

Sincerely,

G. Srinivas
Member Secretary, IEC

A5 Ethical clearance from Malabar Cancer Centre, Thalassery



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No. 1617/IRB-IEC/13/MCC/26-5-2021/ 2 Date: 4th June 2021

DCG(I) Reg. No: ECR/780/Inst./KL/2015/RR-19

To

Dr.Neethu A P
Lecturer in Community Oncology
Department of Community Oncology
Malabar Cancer Centre, Kerala

Subject: IEC Approval Letter-Reg

Dear Dr.Neethu,

The Institutional Ethics Committee reviewed and discussed your application dated 19th May 2021 to conduct the research study entitled "*Breast cancer survival experiences :a retrospective cohort study from 2016 Hospital Based Cancer Registry of a Tertiary Cancer Centre*" during the Institutional Ethics Committee meeting held via tele –conferencing (Zoom meeting) on 26th May 2021 at 2 pm

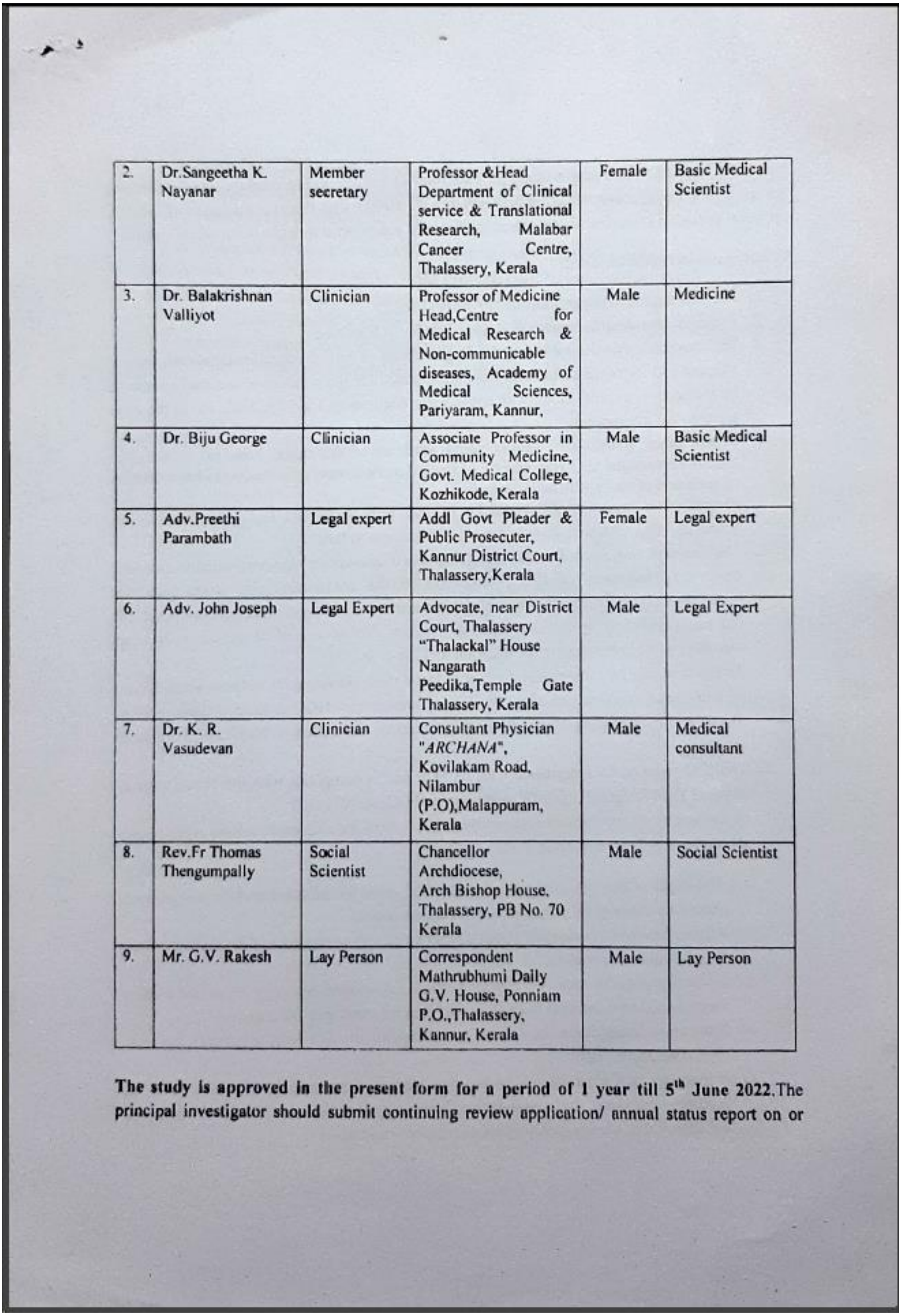
The following documents were reviewed and approved

1. Study Protocol dated 19th May 2021
2. Investigator's Undertaking dated 19th May 2021
3. Patient information sheet and consent form dated 19th May 2021
4. CV, GCP certificate of Principal investigator and Co-investigators dated 19th May 2021

The following members of the IEC-MCC were present the tele- conferencing meeting held on 26th May 2021 at 2:00 PM.

No	Name	Position	Affiliation	Gender	Expertise
1.	Dr. T. N. Babu Ravindran	Chairman	Senior Medical Consultant Indira Gandhi Co-Operative Hospital,Manjodi, Thalassery,Kannur	Male	Medical consultant

Income tax exemption for donations to this centre under Section 80 G of the IT Act 1961



2.	Dr.Sangeetha K. Nayanar	Member secretary	Professor &Head Department of Clinical service & Translational Research, Malabar Cancer Centre, Thalassery, Kerala	Female	Basic Medical Scientist
3.	Dr. Balakrishnan Valliyot	Clinician	Professor of Medicine Head,Centre for Medical Research & Non-communicable diseases, Academy of Medical Sciences, Pariyaram, Kannur,	Male	Medicine
4.	Dr. Biju George	Clinician	Associate Professor in Community Medicine, Govt. Medical College, Kozhikode, Kerala	Male	Basic Medical Scientist
5.	Adv.Preethi Parambath	Legal expert	Addl Govt Pleader & Public Prosecuter, Kannur District Court, Thalassery,Kerala	Female	Legal expert
6.	Adv. John Joseph	Legal Expert	Advocate, near District Court, Thalassery "Thalackal" House Nangarath Peedika,Temple Gate Thalassery, Kerala	Male	Legal Expert
7.	Dr. K. R. Vasudevan	Clinician	Consultant Physician "*ARCHANA*", Kovilakam Road, Nilambur (P.O),Malappuram, Kerala	Male	Medical consultant
8.	Rev.Fr Thomas Thengumpally	Social Scientist	Chancellor Archdiocese, Arch Bishop House, Thalassery, PB No. 70 Kerala	Male	Social Scientist
9.	Mr. G.V. Rakesh	Lay Person	Correspondent Mathrubhumi Daily G.V. House, Ponniam P.O.,Thalassery, Kannur, Kerala	Male	Lay Person

The study is approved in the present form for a period of 1 year till 5th June 2022. The principal investigator should submit continuing review application/ annual status report on or before 5th May 2022.You may request for extension of validity in the submission of continuing review application/annual status report. In order to ensure that there is no lapse in the IEC approval period, it is mandatory to submit study status report prior to lapse of the study validity.

Following points must be noted:

1. IEC has approved the conduct of the study at MCC
2. Principal investigator and study team should be GCP trained
3. IEC mandates that details of any funding received as part of educational/unconditionally support and /or other extramural funding obtained for the conduct of the study needs to be initiated to the IEC along with appropriate documents: Eg-CTA/MoU etc as the PI is privy to the information.
4. PI and other investigators should notify initiation of the study. Principal investigator should intimate the IEC after accrual of first 10 participants in the study or after 6 months of initiation of study whichever is earlier.
5. PI and other investigators should co operate fully with data and safety monitoring board(DSMB), who will monitor the study from time to time
6. The decision was arrived at through consensus/unanimous or majority opinion amongst the voting members of IEC. Member(s) of the committee who is/are listed as investigator(s) on a research proposal opted out from all deliberations on the proposal and did not participate in decision making. Neither PI nor any of proposed study team members participated during the decision making of the IEC.
7. At the time of PI's retirement/intention to leave the institute, study responsibility should be transferred to colleagues after obtaining clearance from HOD or head of the Instituion. Status report, including accounts details should be submitted to HoD and extramural sponsors.
8. The IEC function in accordance with its SOP and is complaint with the New Drugs & Clinical Trail Rules,2019,ICMR guidelines and Indian /ICH GCP
9. In the events of any protocol amendments, IEC must be informed and the amendments should be highlighted in clear terms as follows:

    a) The exact of any protocol amendments, IEC must be informed and the amendments should be the original project(Page no, clause no etc)
    b) Alternation in the budgetary status should be clearly indicated and the revised budget from should be submitted
    c) If the amendments require a change in the consent form, the copy of revised consent form should be submitted to Institutional Ethics Committee for approval
    d) If the amendment demands a relook at the toxicity or side effects to patients, the same should be documents
    e) If there are any amendments in the study design, there must be incorporated in the protocol, and other study comments. These revised documents should be submitted for approval of the IEC, only then can they be implements

    f) Approval of amendment changes must be obtained prior to implementation of changes. Without including all the above points, the amendment is unlikely to be approved by the IEC

10. Any serious Adverse events(SAEs) occurring on the study should be reported to IEC
11. Any deviation/violation/waiver in the protocol must be informed the IEC
12. PI should conduct the study in accordance with the IEC approval
13. The PI should submit a report to the IEC at the time of study completion/premature termination/suspension/discontinuation, as is applicable
14. PI should comply with regulations and guidelines as applicable

Thanking you,

Yours Sincerely

Dr.Sangeetha K Nayanar
IEC-Member Secretary, MCC

Member Secretary
Institutional Ethics Committee
Malabar Cancer Centre
Thalassery, Kerala-670 103

INSTITUTIONAL REVIEW BOARD
MALABAR CANCER CENTRE
THALASSERY
KERALA-670 103

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Participant information sheet

Follow-up survey Study number……………

Breast cancer survivorship experiences: a retrospective cohort study based on cancer registry in northern Kerala
You are asked to participate in a research study conducted by Dr. Neethu A P, a research scholar at Achutha Menon Centre for Health Science Studies. Sree Chitra Tirunal Institute for Medical Science and Technology, Trivandrum, India as part of her PhD dissertation. The study is for evaluating the condition of breast cancer patients who were registered in this hospital in 2016, understanding the present condition and challenges faced by these survivors (disease-free and those living with the disease) in their journey to survival. The study also evaluates their present levels of anxiety and depression and their work ability and return to work challenges.
Before agreeing to participate you must read the following explanation of the study that describes the purpose, benefits, risks, and rights as a study subject.

Title of the study: Breast Cancer Survivorship Experiences: A retrospective cohort study based on Cancer Registry in Northern Kerala
Principle investigator and affiliation: Dr. Neethu A P, PhD scholar, AMCHSS, SCTIMST, TVM and Lecturer, Malabar Cancer Centre, Thalassery

Background: Breast cancer ranks number one cancer in the world among both males and females taken together. As treatment advances the number of breast cancer survivors is increasing. The challenges, long-term treatment effects, levels of anxiety and depression, the difficulty they faced in returning to work, etc. have to be understood to plan their follow-up care and suggest interventions for improving their welfare. Detailed in-depth interviews will help in further understanding their journey through cancer and this might help in formulating breast cancer survivorship plans and indirectly in cancer control strategies.

Details of enrollment: You are asked to participate in this study as you are a patient who is registered in this centre in 2016. You can provide relevant information regarding your present condition, details of any recurrence, your awareness regarding breast cancer, the barriers you faced in the help-seeking process, your present level of anxiety and depression related to the disease, your work ability, and long-term effects of cancer treatment that you have now. We consider you as a person with no other physical or mental condition which prevents your complete participation in the study. If you choose to participate in the study, the principal investigator will interview you. You will be asked questions regarding the above details. Your interview will last for 40-45 minutes. We plan to include all subjects in the 2016 HBCR registry who are now available and willing to participate in the study.

Possible reasonably for seeable risk or discomfort: No risks to you are expected due to participation in the study. The study has no side effects. The only difficulty may be in spending your valuable time for the interview and the uneasiness in going through your experiences in case they are unpleasant.

Benefits of participating in the study: There will be no direct benefits for the subject. The information provided will benefit society as it will guide policymakers in making policies for breast cancer survivorship plans and your experiences with barriers in help-seeking, delay in diagnosis, experiences with long-term medical and psychological effects of treatment, challenges faced in returning to work, etc. will provide further light to these unexplored matters.

Can you withdraw from the study after it starts? Your participation is entirely voluntary and you are free to withdraw your consent. This will not in any way affect your treatment or any other services you avail from this hospital. The investigator may also withdraw you from the study without your agreement.

Anonymity: The results of this study will be published in medical journals, but you will not be identified by name in any publication or presentation of results. However, people associated with this study may review your medical notes, without your additional permission; in case you decide to participate in this study. No one outside the research team will have access to your data.

The information collected from you will be stored with a code number instead of your name. Information collected by this interview will be detached from the consent forms.

Questions /parties to contact: If you have any further questions, please ask Dr. Neethu A P, Principal Investigator (Ph: 9496048812, email neetumcc@gmail.com) or Dr. Srinivas G, Member secretary, Institute Ethics Committee, (Ph.: 0471 2524689, email id iec.mem.sec@sctimst.ac.in) at any time.

If you decide to take part in this research study, you must sign this form to show that you want to take part. You can keep a copy of the form for your reference.

Consent form

I have been given a chance to read and understand the consent form thoroughly.

I understand that I can contact Dr. Neethu A P at any point in time to ask questions regarding my participation in this research study and that I will be answered to my satisfaction.

I understand that my participation in this study is voluntary and I can quit at any time without any problem.

I also understand that the investigator can decide at any point that I should no longer participate in the study.

If I have any questions about my rights as a subject in the study, I may contact Dr. Neethu A P, Ph.D Scholar, AMCHSS, SCTIMST, Trivandrum, Ph.: 9496048812.

I have read and understood the above information. I agree to participate in this study.

I understand that I will be given a copy of this signed and dated form for my own records. I have initialed the boxes below to indicate my consent to complete the interview.

Are you willing to participate? Yes ☐ No ☐

Study Participant (Signature)________________Date________________

Name ____

Signature of Person obtaining consent: ___________________________

Name: ______________________________________Date: ___________

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പഠനവിവര പത്രിക (Follow up survey)

സ്തനാർബുദത്തെ അതിജീവിച്ച അനുഭവങ്ങൾ: വടക്കൻ കേരളത്തിലെ ഒരു ത്രിതീയ കാൻസർ സെന്ററിന്റെ 2016 കാൻസർ രജിസ്ട്രിയിൽ നിന്നുള്ള പഠനം

തിരുവനന്തപുരം ശ്രീത്ര തിരുനാൽ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഫോർ മെഡിക്കൽ സയൻസ് ആൻഡ് ടെക്നോളജിയുടെ ഭാഗമായ അച്ചുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസിന്റെ ഗവേഷണ വിദ്യാർത്ഥി ഡോ. നീതു എ പി, അവരുടെ പിഎച്ച്ഡി പ്രബന്ധത്തിന്റെ ഭാഗമായി നടത്തുന്ന ഗവേഷണ പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങളോട് ആവശ്യപ്പെടുന്നു . 2016 -ൽ ഈ ആശുപത്രിയിൽ രജിസ്റ്റർ ചെയ്ത സ്തനാർബുദ രോഗികളുടെ ഇപ്പോഴത്തെ ആരോഗ്യ അവസ്ഥയും ,അതിന്റെ കാരണങ്ങളും ,അവരുടെ മാനസിക അവസ്ഥ (ഉൽക്കണ്ഠ ,വിഷാദം),ജോലിയിലെ പ്രവർത്തിശേഷി ,അർബുദ അവബോധം ,ആരോഗ്യ പ്രവർത്തകനെ കാണാൻ വൈകിയിട്ടുണ്ടെങ്കിൽ അതിന്റെ കാരണങ്ങൾ തുടങ്ങിയവ മനസ്സിലാക്കുവാനുള്ളതാണ് ഈ പഠനം. പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതിക്കുന്നതിനു മുൻപ് പഠനത്തിന്റെ ലക്ഷ്യങ്ങളും ഉദ്ദേശങ്ങളും അറിഞ്ഞിരിക്കേണ്ടതാണ്

ഗവേഷണ വിഷയം: സ്തനാർബുദത്തെ അതിജീവിച്ച അനുഭവങ്ങൾ: വടക്കൻ കേരളത്തിലെ ഒരു ത്രിതീയ കാൻസർ സെന്ററിന്റെ കാൻസർ രജിസ്ട്രിയിൽ നിന്നുള്ള പഠനം

ഗവേഷക: ഡോ. നീതു എ പി - തിരുവനന്തപുരം ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഫോർ മെഡിക്കൽ സയൻസ് ആൻഡ് ടെക്നോളജിയുടെ ഭാഗമായ അച്ചുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസിന്റെ ഗവേഷണ വിദ്യാർത്ഥി, ലക്ചറർ, മലബാർ കാൻസർ സെന്റർ, തലശ്ശേരി

പഠനപശ്ചാത്തലം :സ്തനാർബുദം ലോകത്ത് മൊത്തം ബാധിക്കുന്ന അർബുദങ്ങളിൽ (പുരുഷന്മാരിലും സ്ത്രീകളിലും) ഒന്നാമതായി നിൽക്കുന്നു . നൂതന ചികിത്സയുടെ ഫലമായി സ്തനാർബുദത്തെ അതിജീവിക്കുന്നവരുടെ എണ്ണം വർദ്ധിച്ചു കൊണ്ടിരി -ക്കുകയാണ്. അവരുടെ തുടർന്നുള്ള പരിചരണം ആസൂത്രണം ചെയ്യുന്നതിനും അവരുടെ ക്ഷേമം മെച്ചപ്പെടുത്തുന്നതിനുള്ള ഇടപെടൽ നിർദ്ദേശിക്കുന്നതിനും ,അവർ നേരിട്ടവെല്ലുവിളികൾ, ദീർഘകാല ചികിത്സാ ഫലങ്ങൾ, അവരുടെ ഉത്കണ്ഠ, വിഷാദം, ജോലിയിലേക്ക് മടങ്ങുന്നതിന് അവർ നേരിട്ട ബുദ്ധിമുട്ട് തുടങ്ങിയവ മനസ്സിലാക്കേണ്ടതുണ്ട്. അഭിമുഖങ്ങളിലൂടെ ക്യാൻസറിലൂടെയുള്ള അവരുടെ യാത്രയെക്കുറിച്ച് കൂടുതൽ മനസിലാക്കാൻ സാധിക്കും, ഇത് സ്തനാർബുദത്തെ അതിജീവിക്കാനുള്ള പദ്ധതികൾ ആവിഷ്കരിക്കുന്നതിനും, പരോക്ഷമായി കാൻസർ നിയന്ത്രണ തന്ത്രങ്ങളിലും സഹായിക്കും .

പഠനപങ്കാളിത്തം:നിങ്ങൾ 2016 ൽ ഈ കേന്ദ്രത്തിൽ രജിസ്റ്റർ ചെയ്തിട്ടുള്ള ഒരു രോഗിയായതിനാൽ ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങളോട് ആവശ്യപ്പെടുന്നു. നിങ്ങളുടെ നിലവിലെ അവസ്ഥ,വീണ്ടും അസുഖം വന്നിട്ടുണ്ടെങ്കിൽ അതിന്റെ വിശദാംശങ്ങൾ,സ്തനാർബുദത്തെക്കുറിച്ചുള്ള അവബോധം, തുടക്കത്തിൽ രോഗനിർണയസമയത് നേരിട്ട തടസ്സങ്ങൾ എന്നിവ സംബന്ധിച്ച പ്രസക്തമായ വിവരങ്ങൾ നിങ്ങൾക്ക് നൽകാൻ കഴിയും.രോഗവുമായി ബന്ധപ്പെട്ട നിങ്ങളുടെ നിലവിലെ ഉത്കണ്ഠ, വിഷാദം, നിങ്ങളുടെ പ്രവർത്തന ശേഷി ,കാൻസർ ചികിത്സയുടെ ദീർഘകാല ഫലങ്ങൾ തുടങ്ങിയവയും ആരായും.പഠനത്തിൽ നിങ്ങളുടെ പൂർണ്ണ പങ്കാളിത്തം തടയുന്ന മറ്റ് ശാരീരികമോ മാനസികമോ ആയ അവസ്ഥകളിലാത്ത ഒരു വ്യക്തിയായി ഞങ്ങൾ നിങ്ങളെ കണക്കാക്കുന്നു. പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങൾ തിരഞ്ഞെടുക്കുക- യാണെങ്കിൽ, മുഖ്യഗവേഷക നിങ്ങളുടെ അഭിമുഖം നടത്തും. മുകളിലുള്ള വിഷയങ്ങളുടെ വിശദാംശങ്ങൾ സംബന്ധിച്ച് നിങ്ങളോട് ചോദ്യങ്ങൾ ചോദിക്കും. നിങ്ങളുടെ അഭിമുഖം 40-45 മിനിറ്റ് നീണ്ടുനിൽക്കും. പഠനത്തിൽ പങ്കെടുക്കാൻ തയ്യാറുള്ളതും ഇപ്പോൾ ലഭ്യമായതുമായ 2016 എച്ച്ബിസിആർ(HBCR) രജിസ്ട്രിയിലെ എല്ലാ സ്തനാർബുദ രോഗികളെയും (ഇപ്പോൾ അതിജീവകർ) ഉൾപ്പെടുത്താൻ ഞങ്ങൾ പദ്ധതിയിടുന്നു.

മുൻകൂട്ടി കണ്ടുപിടിക്കാൻ സാധ്യമായ അപകടങ്ങളും ബുദ്ധിമുട്ടുകളും യാതൊരു തരത്തിലുള്ള ബുദ്ധിമുട്ടുകളും അപകടസാധ്യതകളും ഈ പഠനം കൊണ്ട് ഉണ്ടാവുന്നതല്ല.അഥവാ ഉണ്ടെങ്കിൽ നിങ്ങളുടെ വിലയേറിയ സമയം അഭിമുഖത്തിനായി ചെലവഴിക്കുന്നതിലുള്ള ഒരേയൊരു ബുദ്ധിമുട്ട് മാത്രം.

പഠനത്തിൽ പങ്കെടുക്കുന്നതിന്റെ പ്രയോജനങ്ങൾ: പഠനത്തിൽ പങ്കെടുക്കുന്നത് കൊണ്ട് നിങ്ങൾക്ക് നേരിട്ടുള്ള നേട്ടങ്ങളൊന്നും ഉണ്ടാകില്ല. എന്നാൽ നിങ്ങളുടെ അനുഭവങ്ങളിലൂടെ നൽകിയ വിവരങ്ങൾ സമൂഹത്തിന് ഗുണം ചെയ്യും, കാരണം ഇത് അതിജീവകരുടെ പ്രശ്നങ്ങൾ മനസ്സിലാക്കാനും സ്തനാർബുദ അതിജീവകർക്കുള്ള പദ്ധതികൾക്കായി നയങ്ങൾ നിർമ്മിക്കുന്നതിൽ സഹായിക്കും.

പഠനം ആരംഭിച്ചതിനു ശേഷം എനിക്ക് പിന്മാറാനാകുമോ: നിങ്ങളുടെ പങ്കാളിത്തം പൂർണ്ണമായും സ്വമേധയാ ഉള്ളതാണ്, മാത്രമല്ല മുൻകൂട്ടി കാര്യങ്ങൾ ബോധിപ്പിക്കാതെ തന്നെ സമ്മതം പിൻവലിക്കാൻ നിങ്ങൾക്ക് സ്വാതന്ത്ര്യമുണ്ട്. ഇത് നിങ്ങളുടെ ചികിത്സയെയോ ഈ ആശുപത്രിയിൽ നിന്ന് ലഭിക്കുന്ന മറ്റേതെങ്കിലും സേവനങ്ങളെയോ ഒരു തരത്തിലും ബാധിക്കുകയില്ല. നിങ്ങളുടെ സമ്മതം കൂടാതെ തന്നെ ഗവേഷകനും നിങ്ങളെ പഠനത്തിൽ നിന്ന് പിൻവലിക്കാം.

പഠനവിവരങ്ങളുടെ രഹസ്യസ്വഭാവം: ഈ പഠനത്തിന്റെ ഫലങ്ങൾ മെഡിക്കൽ ജേണലുകളിൽ പ്രസിദ്ധീകരിക്കും, പക്ഷേ ഏതെങ്കിലും പ്രസിദ്ധീകരണത്തിലോ ഫലത്തിന്റെ അവതരണത്തിലോ നിങ്ങളെ തിരിച്ചറിയാൻ കഴിയുന്ന യാതൊരു സൂചനകളും പുറത്തു വിടുന്നതല്ല. ഗവേഷണസംഘത്തിനല്ലാതെ മറ്റാർക്കും ഈ വിവരങ്ങൾ അറിയാൻ സാധിക്കില്ല; ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തീരുമാനിക്കുകയാണെങ്കിൽ നിങ്ങളിൽ നിന്ന് ശേഖരിച്ച വിവരങ്ങൾ നിങ്ങളുടെ പേരിന് പകരം ഒരു കോഡ് നമ്പർ ഉപയോഗിച്ച് സൂക്ഷിക്കുന്നതാണ്.

കൂടുതൽ വിവരങ്ങൾക്ക്: ഈ പഠനവുമായി ബന്ധപ്പെട്ട കൂടുതൽ വിവരങ്ങൾക്ക് നിങ്ങൾക്ക് പ്രധാന ഗവേഷക ഡോ.നീതു എ പി യെ (ഫോൺ: 9496048812,ഇമെയിൽ (neetumcc@gmail.com)) ഇൻസ്റ്റിറ്റ്യൂട്ട് എത്തിക്സ് കമ്മിറ്റി സെക്രട്ടറി ഡോ.ശ്രീനിവാസ് ജി യെയോ (ഫോൺ: 0471 2524689, ഇമെയിൽ (iec.mem.sec@sctimst.ac.in)) ഏത് സമയത്തും ബന്ധപ്പെടാവുന്നതാണ്. ഈ ഗവേഷണ പഠനത്തിൽ പങ്കെടുക്കാൻ തീരുമാനിക്കുകയാണെങ്കിൽ, ഈ ഫോമിൽ ഒപ്പിടേണ്ടതാണ്. ഈ രേഖയുടെ ഒരു പകർപ്പ് നിങ്ങളുടെ അറിവിലേക്കായി നൽകുന്നതാണ്

സമ്മതപത്രം

ഈ ഗവേഷണ പഠനത്തെ ക്കുറിച്ച് നന്നായി വായിക്കാനും മനസിലാക്കാനും എനിക്ക് അവസരം ലഭിച്ചു. സംശയങ്ങൾ ചോദിക്കാൻ എനിക്ക് അവസരം ലഭിക്കുകയും തൃപ്തികരമായ ഉത്തരങ്ങൾ ലഭിക്കുകയും ചെയ്തു. പഠനത്തിലെ എന്റെ പങ്കാളിത്തത്തെക്കുറിച്ച് ചോദിക്കാൻ എപ്പോൾ വേണമെങ്കിലും ഡോ. നീതു എ പി, പിഎച്ച്ഡി വിദ്യാർത്ഥി, AMCHSS, SCTIMST, തിരുവനന്തപുരം, Ph: 9496048812 എന്നിവരുമായി ബന്ധപ്പെടാമെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഈ പഠനത്തിലെ എന്റെ പങ്കാളിത്തം സ്വമേധയാ ഉള്ളതാണെന്നും എനിക്ക് ഒരു പ്രശ്നവുമില്ലാതെ എപ്പോൾ വേണമെങ്കിലും പിന്മാറാമെന്നും മനസ്സിലാക്കുന്നു. എന്റെ സമ്മതം കൂടാതെ തന്നെ ,എന്നെ എപ്പോൾ വേണമെങ്കിലും ഗവേഷകന് പഠനത്തിൽ നിന്ന് പിൻവലിക്കാൻ തീരുമാനിക്കാമെന്നും ഞാൻ മനസ്സിലാക്കുന്നു

സമ്മതപത്രം ഒപ്പ് വെക്കുന്നതിലൂടെ എന്റെ നിയമപരമായ അവകാശങ്ങളൊന്നും തന്നെ ഞാൻ വേണ്ടെന്ന് വെക്കുന്നില്ല. മുകളിലുള്ള വിവരങ്ങൾ വായിച്ചു മനസ്സിലാക്കി ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ ഞാൻ സമ്മതിക്കുന്നു. എന്റെ സ്വന്തം അറിവിലേക്കായി ഒപ്പിട്ടതും തീയതി രേഖപ്പെടുത്തിയതുമായ രേഖയുടെ ഒരു പകർപ്പ് നൽകുമെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു. എന്റെ സമ്മതം സൂചിപ്പിക്കുന്നതിന് അടയാളപ്പെടുത്തിയ സ്ഥലത്തു ഞാൻ ഒപ്പിട്ടു നൽകുന്നു.

ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ എനിക്ക് സമ്മതമാണ്

പഠന പങ്കാളിയുടെ ഒപ്പ് ______________ തീയതി ______________

പഠന പങ്കാളിയുടെ പേര് ____

സമ്മതം ഒപ്പിട്ടുവാങ്ങിയ വ്യക്തിയുടെ ഒപ്പ്: ______________തീയതി: _____________

സമ്മതം ഒപ്പിട്ടു വാങ്ങിയ വ്യക്തിയുടെ പേര്:___________________________________

A8

Participant information sheet

In-depth interview Study number ……………

Breast cancer survivorship experiences: a retrospective cohort study based on Cancer Registry in Northern Kerala

You are asked to participate in a research study conducted by Dr. Neethu A P, a research scholar at Achutha Menon Centre for Health Science Studies. Sree Chitra Tirunal Institute for Medical Science and Technology, Trivandrum, India as part of her PhD dissertation. The study is for evaluating the condition of breast cancer patients who were registered in this hospital in 2016, understanding the present condition and challenges faced by these survivors (disease-free and those living with the disease) in their journey to survival. The study also evaluates their present levels of anxiety and depression and their work ability and return to work challenges. Before agreeing to participate it is important that you read the following explanation of the study that describes the purpose, benefits, risks, and rights as a study subject.

Title of the study: Breast Cancer Survivorship Experiences: A retrospective cohort study based on Cancer Registry in Northern Kerala

Principle investigator and affiliation: Dr. Neethu A P, Ph.D. scholar, AMCHSS, SCTIMST, TVM and Lecturer, Malabar Cancer Centre, Thalassery

Background: Breast cancer ranks number one cancer in the world among both males and females taken together. As treatment advances the number of breast cancer survivors is increasing. The challenges, long-term treatment effects, challenges faced, their levels of anxiety and depression, and the difficulty they faced in returning to work, etc. have to be understood in order to plan their follow-up care and suggest interventions for improving their welfare. Detailed in-depth interviews will help in further understanding their journey through cancer and this might help in formulating breast cancer survivorship plans and indirectly in cancer control strategies.

Details of enrollment

You are asked to participate in this study as you are a person who can provide relevant information regarding your experiences as a survivor. We consider you as a person with no other physical or mental condition that prevents your complete participation in the study. If you choose to participate in the study, the principal investigator will interview you. You will be asked to narrate your journey as a survivor emphasizing your experiences and challenges. Your interview will last for 45 minutes -0ne hour. We plan to include 18 persons in this study.

Possible reasonably for seeable risk or discomfort: No risks to you are expected due to participation in the study. The interview has no side effects. The only difficulty may be in spending your valuable time for the interview or the uneasiness in going through your experiences, in case they are unpleasant

Benefits of participating in the study: There will be no direct benefits for the subject. The information provided will benefit society as it will guide policymakers in making policies for breast cancer survivorship plans and your experiences with barriers in help-seeking, delay in diagnosis, experiences with long-term medical and psychological effects of treatment, challenges faced in returning to work, etc. will provide further light to these unexplored matters.

Can you withdraw from the study after it starts? Your participation is entirely voluntary and you are free to withdraw your consent. This will not in any way affect your treatment or any other services you avail from this hospital. The investigator may also withdraw you from the study without your agreement.

Anonymity: The results of this study will be published in medical journals, but you will not be identified by name in any publication or presentation of results. However, people associated with this study may review your medical notes, without your additional permission; in case you decide to participate in this study. No one outside the research team will have access to your data.

The information collected from you will be stored with a code number instead of your name. Information collected by this interview will be detached from the consent forms.

Questions /parties to contact:

If you have any further questions, please ask
Dr.Neethu A P, Principal Investigator, Ph: 9496048812 email at (neetumcc@gmail.com)
Dr. Srinivas G, Member secretary, Institute Ethics Committee,
Ph.: 0471 2524689, email id (iec.mem.sec@sctimst.ac.in) at any time.

If you decide to take part in this research study, you must sign this form to show that you want to take part. You can keep a copy of the form for your reference.

Consent form

I have been given a chance to read and understand the consent form thoroughly.

I understand that I can contact Dr. Neethu A P at any point in time to ask questions regarding my participation in this research study and that I will be answered to my satisfaction.

I understand that my participation in this study is voluntary and I can quit at any time without any problem.

I also understand that the investigator can decide at any point that I should no longer participate in the study.

If I have any questions about my rights as a subject in the study, I may contact Dr. Neethu A P, Ph.D. Scholar, AMCHSS, SCTIMST, Trivandrum, Ph.: 9496048812.

I have read and understood the above information. I agree to participate in this study.

I understand that I will be given a copy of this signed and dated form for my own records. I have initialed the boxes below to indicate my consent to complete the interview.

Are you willing to participate? Yes ☐ No ☐

Study Participant (Signature)________________Date_______________

Name ____

Signature of Person obtaining consent: ___________________ Date: ___________

Name: ____

A9 പഠനവിവര പത്രിക

(In depth interview)

സ്തനാർബുദത്തെ അതിജീവിച്ച അനുഭവങ്ങൾ: വടക്കൻ കേരളത്തിലെ ഒരു ത്രിതീയ കാൻസർ സെന്ററിന്റെ കാൻസർ രജിസ്ട്രിയിൽ നിന്നുള്ള പഠനം

തിരുവനന്തപുരം ശ്രീത്ര തിരുനാൽ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഫോർ മെഡിക്കൽ സയൻസ് ആൻഡ് ടെക്നോളജിയുടെ ഭാഗമായ അച്ചുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസിന്റെ ഗവേഷണ വിദ്യാർത്ഥിയായ ഡോ. നീതു എ പി, അവളുടെ പിഎച്ച്ഡി പ്രബന്ധത്തിന്റെ ഭാഗമായി നടത്തുന്ന ഗവേഷണ പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങളോട് ആവശ്യപ്പെടുന്നു . 2016 ഈ ആശുപത്രിയിൽ രജിസ്റ്റർ ചെയ്ത സ്തനാർബുദ രോഗികളുടെ ഇപ്പോഴത്തെ ആരോഗ്യ അവസ്ഥയും ,അതിന്റെ കാരണങ്ങളും ,അവരുടെ മാനസിക അവസ്ഥ (ഉൽക്കണ്ട ,വിഷാദം),ജോലിയിലെ പ്രവർത്തനശേഷി ,അർബുദ അവബോധം ,ആരോഗ്യ പ്രവർത്തകനെ കാണാൻ വൈകിയിട്ടുണ്ടെങ്കിൽ അതിന്റെ കാരണങ്ങൾ തുടങ്ങിയവ മനസ്സിലാക്കുവാനുള്ളതാണ് ഈ പഠനം

പഠനത്തിൽ പങ്കെടുക്കാൻ സമ്മതിക്കുന്നതിനു മുൻപ് പഠനത്തിന്റെ ലക്ഷ്യങ്ങളും ഉദ്ദേശങ്ങളും അറിഞ്ഞിരിക്കേണ്ടതാണ്

ഗവേഷണ വിഷയം: സ്തനാർബുദത്തെ അതിജീവിച്ച അനുഭവങ്ങൾ: വടക്കൻ കേരളത്തിലെ ഒരു ത്രിതീയ കാൻസർ സെന്ററിന്റെ കാൻസർ രജിസ്ട്രിയിൽ നിന്നുള്ള പഠനം

ഗവേഷക: ഡോ. നീതു എ പി - തിരുവനന്തപുരം ശ്രീ ചിത്ര തിരുനാൾ ഇൻസ്റ്റിറ്റ്യൂട്ട് ഫോർ മെഡിക്കൽ സയൻസ് ആൻഡ് ടെക്നോളജിയുടെ ഭാഗമായ അച്ചുത മേനോൻ സെന്റർ ഫോർ ഹെൽത്ത് സയൻസ് സ്റ്റഡീസിന്റെ ഗവേഷണ വിദ്യാർത്ഥി, ലക്ചറർ, മലബാർ കാൻസർ സെന്റർ, തലശ്ശേരി

പഠനപശ്ചാത്തലം :സ്തനാർബുദം ലോകത്ത് മൊത്തം ബാധിക്കുന്ന അർബുദങ്ങളിൽ (പുരുഷന്മാരിലും സ്ത്രീകളിലും) ഒന്നാമതായി നിൽക്കുന്നു . നൂതന ചികിത്സയുടെ ഫലമായി സ്തനാർബുദത്തെ അതിജീവിക്കുന്നവരുടെ എണ്ണം വർദ്ധിച്ചു കൊണ്ടിരിക്കുകയാണ്. അവരുടെ തുടർന്നുള്ള പരിചരണം ആസൂത്രണം ചെയ്യുന്നതിനും അവരുടെ ക്ഷേമം മെച്ചപ്പെടുത്തുന്നതിനുള്ള ഇടപെടൽ നിർദ്ദേശിക്കുന്നതിനും , അവർ നേരിട്ടവെല്ലുവിളികൾ,

ദീർഘകാല ചികിത്സാ ഫലങ്ങൾ, അവരുടെ ഉത്കണ്ഠ, വിഷാദം, ജോലിയിലേക്ക് മടങ്ങുന്നതിന് അവർ നേരിട്ട ബുദ്ധിമുട്ട് തുടങ്ങിയവ മനസ്സിലാക്കേണ്ടതുണ്ട്. അഭിമുഖങ്ങളിലൂടെ ക്യാൻസറിലൂടെയുള്ള അവരുടെ യാത്രയെക്കുറിച്ച് കൂടുതൽ മനസിലാക്കാൻ സാധി ക്കും, ഇത് സ്തനാർബുദത്തെ അതിജീവിക്കാനുള്ള പദ്ധതികൾ ആവിഷ്കരിക്കുന്നതിനും, പരോക്ഷമായി കാൻസർ നിയന്ത്രണ തന്ത്രങ്ങളിലും സഹായിക്കും .

പഠനപങ്കാളിത്തം: അർബുദം അതിജീവിച്ച ഒരു വ്യക്തി എന്ന നിലയിൽ / അസുഖത്തോടൊപ്പം ജീവിക്കുന്ന വ്യക്തി എന്ന നിലയിൽ അനുഭവങ്ങളെക്കുറിച്ച് പ്രസക്തമായ വിവരങ്ങൾ നൽകാൻ കഴിയുന്ന ഒരു വ്യക്തിയായതിനാൽ ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങളോട് ആവശ്യപ്പെടുന്നു. പഠനത്തിൽ നിങ്ങളുടെ പൂർണ്ണ പങ്കാളിത്തം തടയുന്ന മറ്റ് ശാരീരികമോ മാനസികമോ ആയ അവസ്ഥകളിലാത്ത ഒരു വ്യക്തിയായി ഞങ്ങൾ നിങ്ങളെ കണക്കാക്കുന്നു. പഠനത്തിൽ പങ്കെടുക്കാൻ നിങ്ങൾ തിരഞ്ഞെടുക്കുകയാണെങ്കിൽ, മുഖ്യ ഗവേഷക നിങ്ങളുടെ അഭിമുഖം നടത്തും. നിങ്ങളുടെ അനുഭവങ്ങൾ വെല്ലുവിളികൾ എന്നിവയ്ക്ക് പ്രത്യേകം ഊന്നൽ നൽകിക്കൊണ്ട് ഒരു അതിജീവകയായ നിങ്ങളുടെ യാത്ര വിവരിക്കാൻ ആവശ്യപ്പെടും. അഭിമുഖം 45 മിനിറ്റ് -1 മണിക്കൂർ നീണ്ടുനിൽക്കും. ഈ പഠനത്തിൽ 25 പേരെ ഉൾപ്പെടുത്താൻ ഞങ്ങൾ പദ്ധതിയിടുന്നു .

മുൻകൂട്ടി കണ്ടുപിടിക്കാൻ സാധ്യമായ അപകടങ്ങളും ബുദ്ധിമുട്ടുകളും യാതൊരു തരത്തിലുള്ള ബുദ്ധിമുട്ടുകളും അപകടസാധ്യതകളും ഈ പഠനം കൊണ്ട് ഉണ്ടാവുന്നതല്ല .അഥവാ ഉണ്ടെങ്കിൽ നിങ്ങളുടെ വിലയേറിയ സമയം അഭിമുഖത്തിനായി ചെലവഴിക്കുന്നതിലുള്ള ഒരേയൊരു ബുദ്ധിമുട്ട് മാത്രം.

പഠനത്തിൽ പങ്കെടുക്കുന്നതിന്റെ പ്രയോജനങ്ങൾ: പഠനത്തിൽ പങ്കെടുക്കുന്നത് കൊണ്ട് നിങ്ങൾക്ക് നേരിട്ടുള്ള നേട്ടങ്ങളൊന്നും ഉണ്ടാകില്ല. എന്നാൽ നിങ്ങളുടെ അനുഭവങ്ങളിലൂടെ നൽകിയ വിവരങ്ങൾ സമൂഹത്തിന് ഗുണം ചെയ്യും, കാരണം ഇത് അതിജീവകരുടെ പ്രശ്നങ്ങൾ മനസ്സിലാക്കാനും സ്തനാർബുദ അതിജീവകർക്കുള്ള പദ്ധതികൾക്കായി നയങ്ങൾ നിർമ്മിക്കുന്നതിൽ സഹായിക്കും

പഠനം ആരംഭിച്ചതിനു ശേഷം എനിക്ക് പിന്മാറാനാകുമോ: നിങ്ങളുടെ പങ്കാളിത്തം പൂർണ്ണമായും സ്വമേധയാ ഉള്ളതാണ്, മാത്രമല്ല മുൻകൂട്ടി കാര്യങ്ങൾ ബോധിപ്പിക്കാതെ തന്നെ

സമ്മതം പിൻവലിക്കാൻ നിങ്ങൾക്ക് സ്വാതന്ത്ര്യമുണ്ട്. ഇത് നിങ്ങളുടെ ചികിത്സയെയോ ഈ ആശുപത്രിയിൽ നിന്ന് ലഭിക്കുന്ന മറ്റേതെങ്കിലും സേവനങ്ങളെയോ ഒരു തരത്തിലും ബാധിക്കുകയില്ല. നിങ്ങളുടെ സമ്മതം കൂടാതെ തന്നെ ഗവേഷകനും നിങ്ങളെ പഠനത്തിൽ നിന്ന് പിൻവലിക്കാം.

പഠനവിവരങ്ങളുടെ രഹസ്യസ്വഭാവം: ഈ പഠനത്തിന്റെ ഫലങ്ങൾ മെഡിക്കൽ ജേണലുകളിൽ പ്രസിദ്ധീകരിക്കും, പക്ഷേ ഏതെങ്കിലും പ്രസിദ്ധീകരണത്തിലോ ഫലത്തിന്റെ അവതരണത്തിലോ നിങ്ങളെ തിരിച്ചറിയാൻ കഴിയുന്ന യാതൊരു സൂചനകളും പുറത്തു വിടുന്നതല്ല. ഗവേഷണസംഘത്തിനല്ലാതെ മറ്റാർക്കും ഈ വിവരങ്ങൾ അറിയാൻ സാധിക്കില്ല; ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ തീരുമാനിക്കുകയാണെങ്കിൽ നിങ്ങളിൽ നിന്ന് ശേഖരിച്ച വിവരങ്ങൾ നിങ്ങളുടെ പേരിന് പകരം ഒരു കോഡ് നമ്പർ ഉപയോഗിച്ച് സൂക്ഷിക്കുന്നതാണ്.

കൂടുതൽ വിവരങ്ങൾക്ക്: ഈ പഠനവുമായി ബന്ധപ്പെട്ട കൂടുതൽ വിവരങ്ങൾക്ക് നിങ്ങൾക്ക് പ്രധാന ഗവേഷക ഡോ.നീതു എ പി (ഫോൺ: 9496048812, ഇമെയിൽ (neetumcc@gmail.com))ഇൻസ്റ്റിറ്റ്യൂട്ട് എത്തിക്സ് കമ്മിറ്റി സെക്രട്ടറി ഡോ.ശ്രീനിവാസ് ജി (ഫോൺ: 0471 2524689, ഇമെയിൽ (iec.mem.sec@sctimst.ac.in)) ഏത് സമയത്തും ബന്ധപ്പെടാവുന്നതാണ്.

ഈ ഗവേഷണ പഠനത്തിൽ പങ്കെടുക്കാൻ തീരുമാനിക്കുകയാണെങ്കിൽ, ഈ ഫോമിൽ ഒപ്പിടേണ്ടതാണ്. ഈ രേഖയുടെ ഒരു പകർപ്പ് നിങ്ങളുടെ അറിവിലേക്കായി നൽകുന്നതാണ്

സമ്മതപത്രം

ഈ ഗവേഷണ പഠനത്തെ ക്കുറിച്ച് നന്നായി വായിക്കാനും മനസിലാക്കാനും എനിക്ക് അവസരം ലഭിച്ചു. സംശയങ്ങൾ ചോദിക്കാൻ എനിക്ക് അവസരം ലഭിക്കുകയും തൃപ്തികരമായ ഉത്തരങ്ങൾ ലഭിക്കുകയും ചെയ്തു

പഠനത്തിലെ എന്റെ പങ്കാളിത്തത്തെക്കുറിച്ച് ചോദിക്കാൻ എപ്പോൾ വേണമെങ്കിലും ഡോ. നീതു എ പി, പിഎച്ച്ഡി വിദ്യാർത്ഥി, AMCHSS, SCTIMST, തിരുവനന്തപുരം, Ph: 9496048812 എന്നിവരുമായി ബന്ധപ്പെടാമെന്നും ഞാൻ മനസ്സിലാക്കുന്നു. ഈ പഠനത്തിലെ എന്റെ പങ്കാളിത്തം സ്വമേധയാ ഉള്ളതാണെന്നും എനിക്ക് ഒരു പ്രശ്നവുമില്ലാതെ എപ്പോൾ വേണമെങ്കിലും പിന്മാറാമെന്നും മനസ്സിലാക്കുന്നു.

എന്റെ സമ്മതം കൂടാതെ തന്നെ ,എന്നെ എപ്പോൾ വേണമെങ്കിലും ഗവേഷകന് പഠനത്തിൽ നിന്ന് പിൻവലിക്കാൻ തീരുമാനിക്കാമെന്നും ഞാൻ മനസ്സിലാക്കുന്നു

സമ്മതപത്രം ഒപ്പ് വെക്കുന്നതിലൂടെ എന്റെ നിയമപരമായ അവകാശങ്ങളൊന്നും തന്നെ ഞാൻ വേണ്ടെന്ന് വെക്കുന്നില്ല.

മുകളിലുള്ള വിവരങ്ങൾ വായിച്ചു മനസ്സിലാക്കി ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ ഞാൻ സമ്മതിക്കുന്നു.

എന്റെ സ്വന്തം അറിവിലേക്കായി ഒപ്പിട്ടതും തീയതി രേഖപ്പെടുത്തിയതുമായ രേഖയുടെ ഒരു പകർപ്പ് നൽകുമെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു. എന്റെ സമ്മതം സൂചിപ്പിക്കുന്നതിന് അടയാളപ്പെടുത്തിയ സ്ഥലത്തു ഞാൻ ഒപ്പിട്ടു നൽകുന്നു.

ഈ പഠനത്തിൽ പങ്കെടുക്കാൻ എനിക്ക് സമ്മതമാണ്

പഠന പങ്കാളിയുടെ ഒപ്പ് ____________ തീയതി ____________

പഠന പങ്കാളിയുടെ പേര് ____

സമ്മതം ഒപ്പിട്ടു വാങ്ങിയ വ്യക്തിയുടെ ഒപ്പ്: ____________തീയതി: ____________

സമ്മതം ഒപ്പിട്ടു വാങ്ങിയ വ്യക്തിയുടെ പേര്: ---------------------------------------

A 10

HBCR –Data collection form

1. Serial No …………………………
2. Name of patient …………………………………………………
3. Age.....................
4. UHID..
5. Homemaker / Employed (specify...................................)
6. Panchayath / Ward/ corporation/ municipality ....
7. Urban/Rural..
8. District...
9. Telephone number...
10. Sex ....Male/female
11. Marital status (1) unmarried (2) married (3) widowed (4) Divorced (5) Separated (6) unknown (7) others..........................
12. Mother tongue (1) English (2) Hindi (3) Kannada (4) Tamil (5) Malayalam (6) Bengali (7) Punjabi (8) others .... (9) unknown
13. Religion (1) Hindu (2) Muslim (3) Christian (4) indigenous faith/others.. (9) Unknown
14. Education (1) illiterate (2) literate (3) Primary (4) middle (5) secondary (6) technical after metric (7) college &above (8) others....... (9) unknown
15. Relative /next of kin accompanying the patient (1) Father (2) Mother (3) Spouse (4) Son/ Daughter (6) Other relatives (7) Friend (8) Neighbour (9) Unknown
16. Date of registration in MCC (DD/MM/YY) ..../........./.................
17. Other source of registration /referral (1) hospital (2) lab (3) nursing home (4) others..
18. Date of first diagnosis (DD/MM/YY) ..../........../.................
    (Date of first attendance to any hospital or earliest of 16 or 17)
19. Diagnostic status during the registration at RI (1) microscopically confirmed (2) suspected microscopically/radiologically (3) suspected clinically/to rule out malignancy (4) others ....(5) unknown
20. Method of diagnosis (1) clinically only (2) microscopy (3) x-ray/imaging techniques (4) others………………………………… ....(6) unknown

21. If it is ‘2’	22. If it is ‘3’
1. HPR of primary	1. mammography
2. HPR of secondary	2. USG
3. Bone marrow	3. MRI
4. cytology of primary	4. CT scan
5 cytology of metastasis	5.others(specify)

23. Complete pathological diagnosis

23.1. Primary site...

23.2. Morphology...

24. Secondary site 1. regional LN 2. Distant mets (Specify)…………………………
25. Laterality (1) Right (3) Left (4) Only 1 site involved R or L unknown (5)B/L involvement
26. Sequence (1) one primary only (2) First of 2 or more primary (3) second of 2 or more primary (4) third of three or more primary (5) fourth of four or more primary (6) fifth of five or more primary (7) sixth of six or more primary (8) unspecified sequence number

27. Details of clinical stage and treatment

27.1. Clinical stage before treatment (1) Localised (2) regional nodes (3) direct extension with regional nodes (4) distant mets (5) not palpable (6) too advanced (7) treated elsewhere (8) recurrence (9) others... (10) Unknown

28. Staging system followed TNM/Ann Arbor
29. TNM staging...
30. Composite stage...
31. Treatment taken before registration at RI (1) yes (2) no (9) unknown
32. If ‘yes’ type of treatment given (1) Surgery (2) Radiotherapy (3) Chemotherapy (4) S+R (5) S+C (6) R+C (7) S+R+C (8) Hormone therapy (9) S+H (10) R+H (11) C+H (12) S+R+H (13) S+C+H (14) R+C+H (15) S+R+C+H (16) others................................... (17) Unknown
33. Performance status before treatment (1) Able to perform daily activities without restriction (2) Restricted in physically strenuous activity, but ambulatory and able to carry out light work (3) Ambulatory and capable of all self-care, but unable to carry out any work: up and above more than 50% of waking hours (4) Capable of only limited self-care; confined to bed or chair more than 50% of waking hours (5) completely disabled; cannot carry on any self-care, totally confined to bed or chair
34. Intention to treat at RI (1) curative /radical (2) palliative (3) pain relief only (4) symptomatic (5) No treatment (6) Unknown
35. Cancer-directed treatment given at RI (1) yes (2) No (3) treatment advised, not accepted (4) Incomplete treatment (5) unknown
36. If ‘yes’ type of treatment given at RI (1) Surgery (2) Radiotherapy (3) Chemotherapy (4) S+R (5) S+C (6) R+C (7) S+R+C (8) Hormone therapy (9) S+H (10) R+H (11) C+H (12) S+R+H (13) S+C+H (14) R+C+H (15) S+R+C+H (16) others................................... (17) Unknown
37. Date of commencement of treatment at RI (DD/MM/YY)
38. Date of completion of initial cancer treatment (----/-----/-----------)
39. Reasons for non-treatment/partial /incomplete treatment at MCC

(1) Declined treatment (2) Advised to take planned treatment outside reporting institution (3) Advised to take symptomatic treatment elsewhere (4) Death during treatment (5) Death before initiating treatment (6) Discontinued because of inability to tolerate treatment (7) Others -- (8) unknown

40. Performance status at follow-up or 6 months whichever is earlier
    (1) Able to perform daily activities without restriction (2) Restricted in physically strenuous activity, but ambulatory and able to carry out light work (3) Ambulatory and capable of all self-care, but unable to carry out any work: up and above more than 50% of waking hours (4) capable of only limited self-care; confined to bed or chair more than 50% of waking hours (5) completely disabled; cannot carry on any self-care, totally confined to bed or chair
41. Disease status at follow-up or 6 months whichever is earlier (1) NED (2) Residual disease (3) Cancer in progression or recurrence (4) Second primary (5) Too advanced/cachexia (6) Dead (7) Others......................... (8) Unknown
42. Date of last contact ------/--------/-------

43. Date of death --------/---------/----------

A11 Questionnaire for follow-up survey of survivors

1. Serial No.

2. Age

3. Place of stay

4. Whether employed 1(Yes 2) No If yes specify……………………….

5. Education 1. illiterate 2. literate 3. primary 4. middle 5. Secondary 6. Technical 7. College and above 8. others…………………………………………………………
9. Unknown

6. Marital status 1. unmarried 2. Married 3. Widow 4. Divorced 5. Separated 6. others ………
7. Unknown

7. Parity 1. nullipara 2.No children 3. Have children, if so, no. of children …………

8. Due follow-up date (DD/MM/YY) …. /……../……..

9. Date of last visit to the hospital (actual FU) DD/MM/YY ……. /……. /…………

10. Do you have any co-morbidity diagnosed after completing treatment? Yes/No

If yes, specify

11. Duration after diagnosis 1. Days 2. Weeks 3. Months 4. Years

12. Vital status 1. Alive 2. Dead 3. Unknown

13. If (1) disease status at follow-up 1. No evidence of disease 2. Residual disease only 3. Recurrence 4. Second primary 5. Distant metastasis (specify) ……………………….
6. Unknown

14. Whether on hormones 1. Yes 2. stopped by self-3. stopped by physician 4. Was not advised

15. Date of diagnosis of recurrence (DD/MM/YY)

16. Mode of diagnosis 1. HPR 2. FNAC 3. Radiology 4. Clinical 5.Others ………….. 6. unknown

17. Composite stage

18. If the answer is ‘4’Anatomical site 1. Specify……………………………………… 2. Unknown
19. Present Stage
20. Pathological diagnosis
21. Date of diagnosis (DD/MM/YY)
22. Whether on treatment now 1. Yes, 2. No 3. unknown
23. If so, what type of treatment 1. Surgery 2. Radiation 3. Chemotherapy 4. Palliative care 5. Others……………………………………………………. 6. Don’t know
24. Whether taking treatment elsewhere 1. Yes, 2. No 3. unknown
25. if not, the reason for not undergoing treatment 1. Declined treatment (2) Advised to take planned treatment outside reporting institution (3) Desired to take symptomatic treatment elsewhere (4) Death during treatment (5) Death before initiating treatment (6) Discontinued because of inability to tolerate treatment (7) others…………………………………………………… (8)Unknown
26. If dead, cause of death 1. Due to cancer 2. Most probably due to cancer 3. intercurrent death 4. Treatment-related death 5. Others (specify)……………………… 6. unknown
27. Date of death (DD/MM/YY)

28. Do you have any of these late complications of cancer treatment?

1. Fatigue	Yes/No
2. Pain	Yes/No
3. Are you on pain medication	Yes/No
4. Lymph edema	Yes/No
5. Numbness or weakness of the upper extremity	Yes/No
6. Shortness of breath	Yes/No
7. Cardiovascular disease	Yes/No
8. Cognitive impairment	Yes/No
9. Symptoms related to osteoporosis	Yes/No
10. Did you undergo any investigations for osteoporosis	Yes/No
11. Infertility	Yes/No
12. Weight gain	Yes/No
13. Oral health issues after treatment	Yes/No

14. Hot flushes	Yes/No
15. Mood changes	Yes/No
16. Change in menstruation	Yes/No

29. These are the reasons which people give for delay in going to a Doctor. Did you experience any of the barriers which led to any delay in diagnosis of your disease?

No.	Questions	Always	Sometimes	No	Don’t know
1.	Embarassment				
2.	Fear				
3.	Worried about wasting doctors time				
4	I find the doctor difficult to talk to				
5	Difficult to get appointment as doctor is busy				
6	No time to see doctor as I am busy				
7	Too many other things to worry about				
8	Difficult to get transportation to go to doctor				
9	Worried whether doctor will diagnose me with cancer				
10	Not feeling confident in discussing symptoms with doctor				
11	Worried about financial burden the disease will bring				
12	Nobody to accompany me to go see a doctor				
13.	Any other reasons				

30. After noticing breast symptoms, when did you visit a health worker …… days/week/month

31. How much do you think each of these can increase your chance of getting breast cancer? Please respond as ‘strongly disagree’, disagree, ’not sure’, agree, ’strongly agree’

Sno	Questions	Strongly disagree	disagree	Not sure	agree	Strongly agree
1	Past history of breast cancer					
2	Close relative with breast cancer					
3	Having children later in life or not a all					
4	Starting periods at an early age					
5	Being overweight(BMI>25)					
6	more than 70 years of age					
7	Late menopause					
8	Doing less than 30 minutes of moderate physical activity at least 5 days a week					
9	Any other					

32. Which of the following do you think is a sign of breast cancer? Please put a tick mark against your response

	yes	no	don't know
Change in position of nipple			
In drawing of nipple			
Pain in one of the breast or arm pit			
Puckering or dimpling of skin of breast			
Bleeding or discharge from nipple			
Lump or thickening in the breast			
Nipple rash			
Redness of skin over breast			
Lump or thickening under armpit			
Changes in size of breast or nipple			

33. Do you perform self breast examination 1. Never 2.Once a week 3.Once a month 4. Once in 6 months 5. don't know
34.Are you confident that you will notice a change in your breast 1. Not at all 2. Slightly confident 3. Fairly confident 4.Very confident 5.Dont know

Work ability Index tool (WAI tool)

1 . Current work ability compared to lifetime best

0-unable to work, 10- work ability at its best

0	1	2	3	4	5	6	7	8	9	10

2. Work ability in relation to the demands of the job

How will you rate work ability with respect to the physical demands of your work

Very good	Rather good	Moderate	Rather poor	Very poor
5	4	3	2	1

3. How would you rate your current work ability with respect to the mental demands of your work?

Very good	Rather good	Moderate	Rather poor	Very poor
5	4	3	2	1

4. **Estimated work impairment due to diseases**

Is your illness or injury a hindrance to your current job? Circle more than one alternative if needed.

There is no hindrance/I have no diseases	6
I am able to do my job but it causes some symptoms	5
I must sometimes slow down my work pace or change my work methods	4
I must often slow down my work pace or change my work methods	3
Because of my disease I feel I am able to do only part-time work	2
In my opinion I am entirely unable to work	1

5. Sick leave during the past year (12 months)

How many whole days have you been off work because of a health problem (disease or health care or for examination) during the past year (12 months)

none at all	at the most 9 days	10 - 24 days	25 - 99 days	100 - 365 days
5	4	3	2	1

6. **Own prognosis of work ability two years from now**

Do you believe that – from the standpoint of your health – you will be able to do your current job two years from now?

Unlikely	not certain	relatively certain
1	4	7

7. Mental resources

Have you recently been able to enjoy your regular daily activities?

Often	rather often	sometimes	rather seldom	never
4	3	2	1	0

Have you recently been active and alert?

Often	rather often	sometimes	rather seldom	never
4	3	2	1	0

Have you recently felt yourself to be full of hope for the future?

Continuously	rather often	sometimes	rather seldom	never
4	3	2	1	0

Total score

GAD7 questionnaire for anxiety

	Over the last 2 weeks on how many days have you been bothered by any of the following	Not at all	Several days	More than half	Every day
1.	Feeling nervous, anxious or on edge	0	1	2	3
2.	Not being able to stop or control worrying	0	1	2	3
3.	Worrying too much about different things	0	1	2	3
4.	Trouble relaxing	0	1	2	3
5.	Being so restless that it is hard to sit	0	1	2	3
6.	Becoming easily annoyed or irritable	0	1	2	3
7.	Feeling afraid as if something awful might happen	0	1	2	3

Total score

PHQ9-Questionaire for depression

Over the last 2 weeks, how many days have you been bothered by any of the following problems?	Not at all	Several Days	More than half of the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself or that you are a failure or let your family down	0	1	2	3
7. Trouble concentrating on things like reading or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed, or the opposite –being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would have been better off dead or hurting yourself in some way	0	1	2	3
PHQ Total score				

If you ticked off any problems how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

A12 **സർവ്വേ ചോദ്യാവലി** (follow up survey questionnaire)

1.ക്രമ നമ്പർ:

2. വയസ്സ്:

3. താമസിക്കുന്ന സ്ഥലം:

4. നിലവിൽ ജോലി ചെയ്യുന്നുണ്ടോ 1) ഉണ്ട് 2) ഇല്ല

വിവരിക്കുക..

5. വിദ്യാഭ്യാസം: 1. നിരക്ഷര 2. എഴുത്തും വായനയും അറിയാം. 3. അഞ്ചാം ക്ലാസ് 4. ഏഴാം ക്ലാസ് 5 പ്ലസ് ടു. 6. കോളേജ് 7. മറ്റുള്ളവ.. 8...അറിയില്ല

6. വൈവാഹിക നില:.1. അവിവാഹിത 2. വിവാഹിത 3. വിധവ 4. വിവാഹ മോചിത 5. പിരിഞ്ഞുനിൽക്കുന്നു 6. അറിയില്ല 7. മറ്റുള്ളവ

7. കുട്ടികൾ 1. പ്രസവിച്ചിട്ടില്ല 2. കുട്ടികൾ ഇല്ല 3. കുട്ടികൾ ഉണ്ട് 4. കുട്ടികളുടെ

എണ്ണം......................................

8.നിർദേശിച്ച അവസാന ഫോളോ അപ്പ് തീയതി (DD/MM/YY)

9. അവസാനമായി ആശുപത്രിയിൽ വന്ന ദിവസം (DD/MM/YY)

10.ചികിത്സ പൂർത്തിയാക്കിയതിന് ശേഷം നിങ്ങൾക്ക് എന്തെങ്കിലും മറ്റു രോഗാവസ്ഥയുണ്ടോ എന്ന് വ്യക്തമാക്കുക

11. നിർണ്ണയിച്ചിട്ട് എത്ര കാലമായി 1. ദിവസങ്ങൾ 2. ആഴ്ച 3. മാസം 4. വർഷം

12. രോഗിയുടെ ഇപ്പോഴത്തെ അവസ്ഥ 1. ജീവിച്ചിരിപ്പുണ്ട് 2. മരണപ്പെട്ടു. 3.അറിയില്ല

13. ഉത്തരം(1) എന്നാണെങ്കിൽ അവസാന ഫോളോ അപ്പ് സമയത്തെ രോഗത്തിന്റെ അവസ്ഥ 1. ഇപ്പോൾ രോഗമില്ല 2. രോഗമുണ്ട് ,ലക്ഷണങ്ങളില്ല 3. സ്തനങ്ങളിൽ രണ്ടാമത്

രോഗം 4. മറ്റേതെങ്കിലും തരം അർബുദം 5. വിദൂര അവയവങ്ങളിലേക്കു പടർന്നിരിക്കുന്നു (വ്യക്തമാക്കുക) .... 6. അറിയില്ല

14. ഇപ്പോൾ ഹോർമോൺ ഗുളികകൾ കഴിക്കുന്നുണ്ടോ

1. കഴിക്കുന്നുണ്ട് 2. സ്വയം നിർത്തിയത് 3. ഡോക്ടറുടെ നിർദേശപ്രകാരം നിർത്തിയത് 4. നിർദ്ദേശിച്ചിട്ടില്ല

15. രോഗനിർണയ തീയതി (recurrence) DD/MM/YY

16. രോഗനിർണയ രീതി 1.ഹിസ്റ്റോ പാത്തോളജി 2. എഫ്എൻ എ സി 3. റേഡിയോളജി 4. ക്ലിനിക്കൽ 5. മറ്റുള്ളവ .... 6. അറിയില്ല

17. ഇപ്പോഴത്തെ സ്റ്റേജ് ....

18. രണ്ടാമത്തെ അർബുദം ബാധിച്ച അവയവം .... 2. അറിയില്ല

19. ഇപ്പോഴത്തെ സ്റ്റേജ് ....

20. പാത്തോളജിക്കൽ ഡയഗ്നോസിസ്

21. രോഗനിർണയ തീയതി (DD/MM/YY)

22. ഇപ്പോൾ ചികിത്സ എടുക്കുന്നുണ്ടോ   1 ഉണ്ട്. 2. ഇല്ല 3. അറിയില്ല

23. അങ്ങനെയാണെങ്കിൽ, ഏതുതരം ചികിത്സ 1. സർജറി 2. റേഡിയേഷൻ 3. കിമോ തെറാപ്പി 4 പാലിയേറ്റിവ് / സാന്ത്വന പരിചരണം .5. മറ്റുള്ളവ .... 5. അറിയില്ല

24. മറ്റെവിടുന്നെങ്കിലും ചികിത്സ എടുക്കുന്നുണ്ടോ

25. ചികിത്സ എടുക്കുന്നില്ലെങ്കിൽ, ചികിത്സ എടുക്കാത്തതിന്റെ കാരണം.

1 . ചികിത്സ നിരസിച്ച 2. റിപ്പോർട്ടിംഗ് സ്ഥാപനത്തിന് പുറത്ത് ആസൂത്രിതമായ ചികിത്സ സ്വീകരിക്കാൻ നിർദേശിച്ചതിനാൽ 3. മറ്റെവിടെയെങ്കിലും ചികിത്സ സ്വീകരിക്കാൻ ആഗ്രഹിച്ചതിനാൽ 4. ചികിത്സയ്ക്കിടെ മരണം 5. ചികിത്സ ആരംഭിക്കുന്നതിന് മുമ്പുള്ള മരണം 6. ചികിത്സ സഹിക്കാൻ കഴിയാത്തതിനാൽ നിർത്തലാക്കി

7.മറ്റുള്ളവ………………………………………………… 8. അറിയില്ല

26. മരണപ്പെട്ടെങ്കിൽ, മരണകാരണം   1 കാൻസർ കാരണം 2. മിക്കവാറും കാൻസർ മൂലമാണ് 3. ഇടക്കാല മരണം 4. ചികിത്സയുമായി ബന്ധപ്പെട്ട മരണം 5. മറ്റുള്ളവ (വ്യക്തമാക്കുക)... 6. അറിയില്ല

27. മരണപ്പെട്ട തീയ്യതി   (DD/MM/YY)

28. കാൻസർ ചികിത്സയുടെ എന്തെങ്കിലും വിദൂര ഫലങ്ങൾ നിങ്ങൾക്കുണ്ടോ?

1.ക്ഷീണം	ഉണ്ട്/ഇല്ല
2. വേദന	ഉണ്ട്/ഇല്ല
3.നിങ്ങൾ വേദന സംഹാരികൾ കഴിക്കുന്നുണ്ടോ	ഉണ്ട്/ഇല്ല
4.കൈകളിൽ നീര്	ഉണ്ട്/ഇല്ല
5.കൈകൾക്കു തരിപ്പ് /ബലഹീനത	ഉണ്ട്/ഇല്ല
6.ശ്വാസം മുട്ടൽ	ഉണ്ട്/ഇല്ല
7.ഹൃദയ രോഗങ്ങൾ	ഉണ്ട്/ഇല്ല
8.തിരിച്ചറിയൽ സംബന്ധിച്ച ബുദ്ധിമുട്ടുകൾ	ഉണ്ട്/ഇല്ല
9.അസ്ഥിതേയ്മാനവുമായി ബന്ധപ്പെട്ട ലക്ഷണങ്ങൾ	ഉണ്ട്/ഇല്ല
10.അസ്ഥിതേയ്മാനം നിർണയിക്കാനുള്ള ടെസ്റ്റ് നടത്തിയിട്ടുണ്ടോ	ഉണ്ട്/ഇല്ല
11.വന്ധ്യത	ഉണ്ട്/ഇല്ല

12.കൂടിയ ശരീരഭാരം	ഉണ്ട്/ഇല്ല
13. ചികിത്സയ്ക്കുശേഷം വായിലെ ആരോഗ്യ പ്രശ്നങ്ങൾ	ഉണ്ട്/ഇല്ല
14 ആർത്തവ വിരാമത്തിനു ശേഷം ഉണ്ടാകുന്ന അത്യുഷ്ണ അനുഭവം	ഉണ്ട്/ഇല്ല
15.വൈകാരിക മാറ്റങ്ങൾ	ഉണ്ട്/ഇല്ല
16. ആർത്തവത്തിലെ മാറ്റം	ഉണ്ട്/ഇല്ല

29 .ഡോക്ടറെ കാണാൻ പോകുന്നതിന് കാലതാമസത്തിന് ആളുകൾ നൽകുന്ന കാരണങ്ങൾ ഇവയാണ്. നിങ്ങളുടെ രോഗനിർണയം വൈകുന്നതിന് കാരണമായ എന്തെങ്കിലും തടസ്സങ്ങൾ നിങ്ങൾ അനുഭവിച്ചിട്ടുണ്ടോ?

No.	ചോദ്യങ്ങൾ	എല്ലായ്പ്പോഴും	ചില പ്പോൾ	അല്ല	അറിയില്ല
1.	നാണക്കേട്/ ചമ്മൽ				
2.	ഭയം				
3.	ഡോക്ടർമാരുടെ സമയം പാഴാക്കുമോ എന്ന ആശങ്ക				
4	ഡോക്ടറുമായി സംസാരിക്കാൻ എനിക്ക് ബുദ്ധിമുട്ടാണ്				
5	ഡോക്ടർ തിരക്കിലായതിനാൽ അപ്പോയിന്റ്മെന്റ് ലഭിക്കാൻ പ്രയാസമാണ്				
6	ഞാൻ തിരക്കിലായതിനാൽ ഡോക്ടറെ കാണാൻ സമയമില്ല				
7	വിഷമിക്കേണ്ട മറ്റ് നിരവധി കാര്യങ്ങൾ				
8	ഡോക്ടറെ കാണാൻ പോകാൻ ഗതാഗതം ലഭിക്കാൻ പ്രയാസമാണ്				
9	എനിക്ക് കാൻസർ ഉണ്ടെന്നു ഡോക്ടർ കണ്ടുപിടിക്കുമോ എന്ന ആശങ്ക				
10	രോഗലക്ഷണങ്ങൾ ഡോക്ടറുമായി ചർച്ച ചെയ്യുന്നതിൽ ആത്മവിശ്വാസം തോന്നുന്നില്ല				
11	രോഗം കൊണ്ടുവരുംസാമ്പത്തിക ബാധ്യതയെക്കുറിച്ച് ആശങ്ക				
12	ഒരു ഡോക്ടറെ കാണാൻ പോകാൻ എന്നോടൊപ്പം വരാൻ ആരും ഇല്ല				
13.	മറ്റെന്തെങ്കിലും കാരണങ്ങൾ				

30 നിങ്ങളുടെ സ്തനത്തിലെ മാറ്റം ശ്രദ്ധയിൽപ്പെട്ടതിന് ശേഷം എത്ര ദിവസത്തിനുള്ളിൽ നിങ്ങൾ ഒരു ആരോഗ്യ പ്രവർത്തകനെ സമീപിച്ചു

.... .ദിവസങ്ങൾ / ആഴ്ച / മാസം

31. ഇവയിൽ ഓരോന്നും സ്തനാർബുദം വരാനുള്ള സാധ്യത വർദ്ധിപ്പിക്കുമെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ? നിങ്ങളുടെ പ്രതികരണത്തിനെതിരെ ഒരു ടിക്ക് മാർക്ക് ഇടുക

S.No	ചോദ്യങ്ങൾ	പൂർണമായി വിയോജിക്കുന്നു	വിയോജിക്കുന്നു	ഉറപ്പില്ല	യോജിക്കുന്നു	പൂർണമായി യോജിക്കുന്നു
1	മുൻപ് സ്തനാർബുദം വന്നവർ					
2	അടുത്ത ബന്ധുവിനു സ്തനാർബുദം					
3	കുട്ടികൾ ഉണ്ടാകാൻ വൈകിയവർ/ പ്രസവിക്കാത്തവർ					
4	നേരത്തെ ആർത്തവം ആരംഭിക്കുന്നത്					
5	അമിതമായ ശരീര ഭാരം ഉണ്ടാകുക					
6	70 വയസ്സിനു മുകളിൽ പ്രായം					
7	വൈകി ആർത്തവവിരാമം					
8.	ആഴ്ചയിൽ 5 ദിവസമെങ്കിലും 30മിനിറ്റിൽ താഴെയുള്ള മിതമായ ശാരീരിക അധ്വാനം ചെയ്യാതിരിക്കുക					
9	മറ്റെന്തെങ്കിലും					

32. ഇനിപ്പറയുന്നവയിൽ ഏതാണ് സ്തനാർബുദത്തിന്റെ ലക്ഷണമെന്നാണ് നിങ്ങൾ കരുതുന്നത്?

നിങ്ങളുടെ പ്രതികരണത്തിനെതിരെ ഒരു ടിക്ക് മാർക്ക് ഇടുക

	അതെ	അല്ല	അറിയില്ല
മുലക്കണ്ണിനു സ്ഥാന മാറ്റം			
ഉൾവലിഞ്ഞ മുലക്കണ്ണ്			
സ്തനങ്ങളിലോ കക്ഷങ്ങളിലോ വേദന			
സ്തനങ്ങളിലെ തൊലിപ്പുറത്തുള്ള ചുളിവുകൾ /കുഴികൾ			
മുലക്കണ്ണിൽ നിന്ന് രക്തം കലർന്ന സ്രവം അല്ലെങ്കിൽ ഡിസ്ചാർജ്			
സ്തനങ്ങളിൽ മുഴ/ തടിപ്പ്			
മുലക്കണ്ണിൽ വ്രണം			
സ്തനത്തിലെ ചർമ്മത്തിൽ ചുവപ്പ് നിറം			
കക്ഷങ്ങളിൽ മുഴ /തടിപ്പ്			
സ്തനാകൃതിയിലോ മുലക്കണ്ണിന്റെ ആകൃതിയിലോ അടുത്തകാലത്തുണ്ടായ മാറ്റം			

33.നിങ്ങൾ സ്വയം സ്തന പരിശോധന നടത്താറുണ്ടോ ?1. ഒരിക്കലും ഇല്ല 2. ആഴ്ചയിൽ ഒരിക്കൽ 3. മാസത്തിൽ ഒരിക്കൽ 4. ആറു മാസത്തിൽ ഒരിക്കൽ 5. അറിയില്ല

34. സ്വയം പരിശോധനയിലൂടെ സ്തനങ്ങളിലെ മാറ്റം കണ്ടുപിടിക്കാമെന്നു നിങ്ങൾക്ക് ആത്മവിശ്വാസമുണ്ടോ? 1. തീരെ ആത്മവിശ്വാസമില്ല 2. കുറച്ചു ആത്മവിശ്വാസമുണ്ട് 3. ആത്മവിശ്വാസമുണ്ട് 4. നല്ല ആത്മവിശ്വാസമുണ്ട് 5. അറിയില്ല

ജോലി /പ്രവർത്തന ശേഷി സംബന്ധിച്ച ചോദ്യങ്ങൾ

1. ഇതുവരെ ഉള്ള ജീവിതവുമായി താരതമ്യപ്പെടുത്തുമ്പോൾ നിലവിലെ നിങ്ങളുടെ പ്രവൃത്തി ചെയ്യാനുള്ള കഴിവ്

(0–പ്രവർത്തിക്കാൻ കഴിയുന്നില്ല, 10 മികച്ച പ്രവർത്തന ശേഷി)

0	1	2	3	4	5	6	7	8	9	10

2. ജോലിയുടെ ആവശ്യങ്ങളുമായി ബന്ധപ്പെട്ട് പ്രവൃത്തി ചെയ്യാനുള്ള നിങ്ങളുടെ കഴിവ്:--

ജോലിയുടെ ശാരീരിക ആവശ്യങ്ങളുമായി ബന്ധപ്പെട്ട് നിങ്ങളുടെ നിലവിലെ പ്രവർത്തന ശേഷിയെ എങ്ങനെ വിലയിരുത്തും

വളരെ നല്ലത്	5
താരതമ്യേന നല്ലത്	4
മിതമായത്	3
താരതമ്യേന മോശം	2
വളരെ മോശം	1

3. ജോലിയുടെ മാനസിക ആവശ്യങ്ങളുമായി ബന്ധപ്പെട്ട് നിങ്ങളുടെ പ്രവർത്തന ശേഷിയെ എങ്ങനെ വിലയിരുത്തും?

വളരെ നല്ലത്	5
താരതമ്യേന നല്ലത്	4
മിതമായത്	3
താരതമ്യേന മോശം	2
വളരെ മോശം	1

4 രോഗങ്ങൾ മൂലം കണക്കാക്കപ്പെടുന്ന ജോലിയിലെ ബുദ്ധിമുട്ടുകൾ :--
നിങ്ങളുടെ അസുഖം നിങ്ങളുടെ നിലവിലെ പ്രവർത്തന ശേഷിക്ക് തടസ്സമാണോ? (ആവശ്യമെങ്കിൽ ഒന്നിൽ കൂടുതൽ അടയാളപ്പെടുത്താം.)

ഒരു തടസ്സവുമില്ല / എനിക്ക് രോഗങ്ങളൊന്നുമില്ല	6
എനിക്ക് എന്റെ ജോലി ചെയ്യാൻ കഴിയും, പക്ഷേ ഇത് ചില ബുദ്ധിമുട്ടുകൾ ഉണ്ടാക്കുന്നു	5

ചിലപ്പോൾ എന്റെ ജോലി വേഗത കുറയ്ക്കുകയോ ജോലി രീതികൾ മാറ്റുകയോ ചെയ്യേണ്ടിവരുന്നു	4
പലപ്പോഴും എന്റെ ജോലി വേഗത കുറയ്ക്കുകയോ ജോലി രീതികൾ മാറ്റുകയോ ചെയ്യേണ്ടിവരുന്നു	3
എന്റെ രോഗം കാരണം എനിക്ക് പാർട്ട് ടൈം ജോലി മാത്രമേ ചെയ്യാൻ കഴിയൂ എന്ന് തോന്നുന്നു	2
എന്റെ അഭിപ്രായത്തിൽ എനിക്ക് ജോലി ചെയ്യാൻ പൂർണ്ണമായും കഴിയില്ല	1

5. കഴിഞ്ഞ ഒരു വർഷത്തിൽ അസുഖം കാരണം എടുത്ത അവധി ദിവസങ്ങൾ:--

കഴിഞ്ഞ ഒരു വർഷത്തിൽ(12 മാസത്തിൽ) ആരോഗ്യ കാരണങ്ങളാൽ (പരിശോധന /തുടർസന്ദർശനം തുടങ്ങിയവയ്ക്ക്) നിങ്ങൾക്ക് എത്ര ദിവസം അവധി എടുക്കേണ്ടി വന്നു

എടുത്തിട്ടില്ല	5
9 ദിവസം വരെ	4
10 -24 ദിവസം	3
25 -99 ദിവസം	2
100 - 365 ദിവസം	1

6. ഇപ്പോൾ മുതൽ രണ്ട് വർഷം കഴിഞ്ഞാലുള്ള പ്രവർത്തന ശേഷിയുടെ സ്വയം പ്രവചനം:--

നിങ്ങളുടെ അസുഖത്തിന്റെ കാര്യം വച്ച് നോക്കുകയാണെങ്കിൽ - നിങ്ങളുടെ നിലവിലെ ജോലി

ഇന്നുമുതൽ രണ്ടു വർഷം കഴിഞ്ഞാലും ചെയ്യാൻ കഴിയുമെന്ന് നിങ്ങൾ വിശ്വസിക്കുന്നുണ്ടോ?

സാധ്യതയില്ല	1
ഉറപ്പില്ല	4
താരതമ്യേന ഉറപ്പാണ്	7

7. മാനസിക അവസ്ഥ:--

നിങ്ങളുടെ പതിവ് ദൈനംദിന പ്രവർത്തനങ്ങൾ ആസ്വദിക്കാൻ നിങ്ങൾക്ക് അടുത്തിടെ സാധിച്ചിട്ടുണ്ടോ?

എപ്പോഴും	4
മിക്കപ്പോഴും	3
ചിലപ്പോൾ	2
എപ്പോഴെങ്കിലും	1
ഒരിക്കലും ഇല്ല	0

നിങ്ങൾ അടുത്തിടെ സജീവവും ഊർജസ്വലതയുള്ളവളുമാണോ?

എപ്പോഴും	4
മിക്കപ്പോഴും	3

ചിലപ്പോൾ	2
എപ്പോഴെങ്കിലും	1
ഒരിക്കലും ഇല്ല	0

ഭാവിയെക്കുറിച്ചു ചിന്തിക്കുമ്പോൾ ശുഭപ്രതീക്ഷകൾ നിറഞ്ഞതായി നിങ്ങൾക്ക് അടുത്തിടെ തോന്നിയിട്ടുണ്ടോ?

എപ്പോഴും	4
മിക്കപ്പോഴും	3
ചിലപ്പോൾ	2
എപ്പോഴെങ്കിലും	1
ഒരിക്കലും ഇല്ല	0

മൊത്തം സ്കോർ

മാനസിക ആരോഗ്യത്തെ കുറിച്ചുള്ള ചോദ്യാവലി

	കഴിഞ്ഞ രണ്ടാഴ്ചയിൽ താഴെ കൊടുത്തിരിക്കുന്ന പ്രശ്നങ്ങൾ കാരണം എത്ര കൂടെക്കൂടെ നിങ്ങള്ക്ക് ബുദ്ധിമുട്ടുണ്ടായി *(നിങ്ങളുടെ ഉത്തരം സൂചിപ്പിക്കുന്നതിനായി "√" അടയാളം ഉപയോഗിക്കുക)*	ഒട്ടുമില്ല	നിരവധി ദിവസങ്ങൾ	പകുതിയിൽ കൂടുതൽ ദിവസങ്ങൾ	മിക്കവാറും എല്ലാ ദിവസവും
1.	മനോബലം ഇല്ലാതിരിക്കുക , ഉൽക്കണ്ഠയോ കടുത്ത പിരിമുറുക്കമോ തോന്നുക	0	1	2	3
2.	വിഷമിക്കുന്നത് നിർത്തുവാനോ നിയന്ത്രിക്കാനോ കഴിയാതിരിക്കുക	0	1	2	3
3.	പല കാര്യങ്ങളെക്കുറിച്ചു വളരെയധികം ആശങ്കപ്പെടുക	0	1	2	3
4.	ആശ്വാസം കിട്ടാൻ ബുദ്ധിമുട്ട്	0	1	2	3
5.	അസ്വസ്ഥത മൂലം അനങ്ങാതെ ഇരിക്കാൻ പറ്റാതിരിക്കുക	0	1	2	3
6.	എളുപ്പത്തിൽ പ്രകോപിതനാകുകയോ ശുണ്ഠിയെടുക്കുകയോ ചെയ്യുക	0	1	2	3
7.	ഭയാനകമായ എന്തെങ്കിലും സംഭവിച്ചേക്കാമെന്ന പേടി തോന്നുക	0	1	2	3
	സ്കോർ മൊത്തം സ്കോർ				

ആരോഗ്യത്തെ കുറിച്ചുള്ള ചോദ്യാവലി (PHQ9)

കഴിഞ്ഞ രണ്ടാഴ്ചയിൽ താഴെ കൊടുത്തിരിക്കുന്ന പ്രശ്നങ്ങൾ താങ്കളെ എത്രത്തോളം തുടർച്ചയായി ബുദ്ധിമുട്ടിച്ചു (നിങ്ങളുടെ ഉത്തരം സൂചിപ്പിക്കുന്നതിനായി "√ " അടയാളം ഉപയോഗിക്കുക)	ഒട്ടുമില്ല	നിരവധി ദിവസങ്ങൾ	പകുതിയിൽ കൂടുതൽ ദിവസങ്ങൾ	മിക്കവാറും എല്ലാ ദിവസവും
1. കാര്യങ്ങൾ ചെയ്യാൻ താൽപര്യക്കുറവ് അല്ലെങ്കിൽ സന്തോഷക്കുറവ്	0	1	2	3
2. മനസ്സിടിഞ്ഞതുപോലെയും, വിഷാദവും നിരാശയും തോന്നുന്നു	0	1	2	3
3. ഉറങ്ങിത്തുടങ്ങുന്നതിനോ ഉറക്കം തുടരുന്നതിനോ ബുദ്ധിമുട്ടു അല്ലെങ്കിൽ വളരെ അധികം ഉറങ്ങുന്നു	0	1	2	3
4. തളർന്നവശനാണെന്നോ, ക്ഷീണിതനാണെന്നോ തോനുന്നു	0	1	2	3
5. വിശപ്പില്ലായ്മ അല്ലെങ്കിൽ അമിതഭക്ഷണം	0	1	2	3
6. സ്വയം നിന്ദ തോനുന്നു അല്ലെങ്കിൽ നിങ്ങൾ ഒരു പരാജയമാണെന്നോ നിങ്ങളുടെ കുടുംബത്തിന് ചീത്തപ്പേരുണ്ടാക്കിയെന്നോ തോനുന്നു	0	1	2	3
7. പത്രം വായിക്കുകയോ, ടീവി കാണുകയോ പോലെയുള്ള കാര്യങ്ങളിൽ ശ്രദ്ധ പതിപ്പിക്കാൻ പ്രയാസമനുഭവപ്പെടുന്നു	0	1	2	3
8. മറ്റുള്ളവർ ശ്രദ്ധിക്കത്തക്കവിധം സാവധാനം ചലിക്കുകയോ സംസാരിക്കുകയോ ചെയ്യുന്നുണ്ടോ ? അല്ലങ്കിൽ നേരെ വിപരീതമായി - പതിവിൽ കൂടുതൽ ചലിക്കുന്നവിധം അമിതമായ അസ്വസ്ഥതയോ ചാഞ്ചല്യമോ അനുഭവപ്പെടുന്നു	0	1	2	3
9. മരിക്കുന്നതാണ് നല്ലതെന്നോ , ഏതെങ്കിലും രീതിയിൽ മുറിവേൽപ്പിച്ചിരുന്നെങ്കിൽ നന്നായിരുന്നേനെ എന്നോ ,ചിന്തിക്കുന്നു	0	1	2	3
സ്കോർ മൊത്തം സ്കോർ				

നിങ്ങൾ ഏതെങ്കിലും പ്രശ്നം അടയാളപ്പെടുത്തിയിട്ടുണ്ടെങ്കിൽ ആ പ്രശ്നങ്ങൾ നിങ്ങളുടെ ജോലി ചെയ്യുന്നതിനും, വീട്ടിലെ കാര്യങ്ങൾ നാടത്തുന്നതിനും ,മറ്റുള്ളവരുമായി സഹകരിച്ചു പോകുന്നതിനും എത്രത്തോളം ബുദ്ധിമുട്ടുണ്ടാക്കിയിട്ടുണ്ട്

ഒട്ടും ബുദ്ധിമുട്ടില്ല	അൽപ്പം ബുദ്ധിമുട്ടുണ്ട്	വളരെ ബുദ്ധിമുട്ടുണ്ട്	അങ്ങേയറ്റം ബുദ്ധിമുട്ടുണ്ട്

A13

Checklist for in-depth interviews of survivors for survivor experiences

A. In-depth interview checklist for disease-free survivors

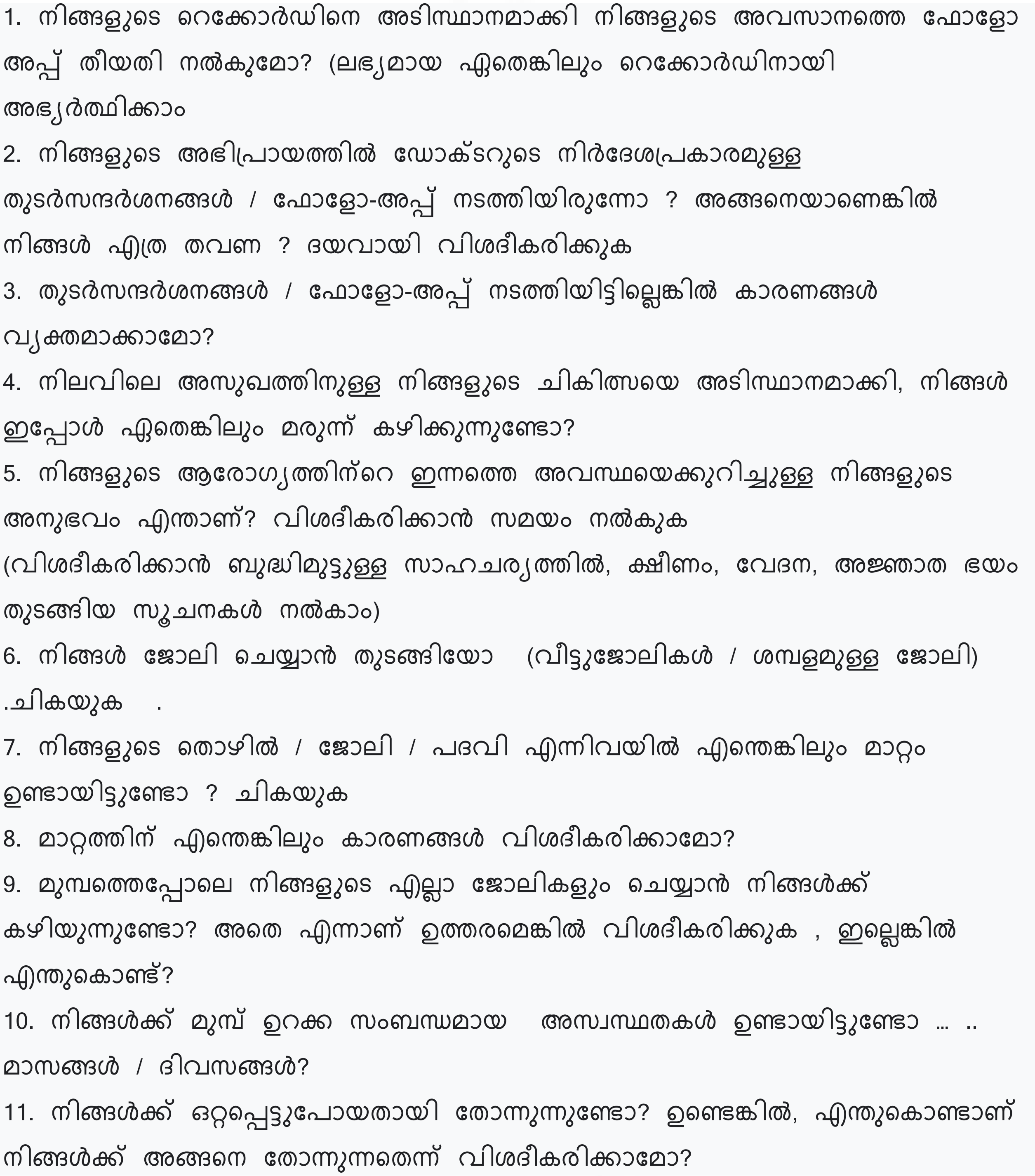
1. Will you please give the date of your last follow-up based on your record? (May request for any available record)
2. According to you was the follow-up regular? If so, how frequently you went? Please explain.
3. If not followed up, please state the reasons.
4. Based on your current illness treatment, are you on any medication?
5. What is your experience of the present status of your health? Give time to explain. In case of difficulty, may give hints like feeling tired, having pain, unknown fear, etc
6. Are you back to work (household chores/salaried job) Probe
7. Any change in your occupation/job/designation Probe.
8. Can you explain any reasons for the change?
9. Are you able to do all your work as earlier? If yes, how, and if no, why?
10. Do you have any sleep disturbances in the past….? Months/days?
11. Do you feel lonely? If yes, will you please explain why you feel so?
12. Are you happy with your present situation or have you thought any time that it was far better if I have not lived through this or similar feeling?
13. Are you more active now or are you feeling withdrawn?
14. Did you lose your hair as part of your treatment? What were your feelings then? Has your hair grown back now?
15. Have you experienced any stigma from your neighbors, friends, or family (attending functions, difficulty in getting your daughter married (etc.)? Probe
16. What is the attitude of your children towards you now? Any change in attitude experienced by you?
17. What is the attitude of your husband towards you at present? Any change in attitude from previous years?
18. What is the attitude of your friends towards you at present? Any change in attitude from previous years?
19. What is the attitude of your in-laws towards you? Did you notice any change from previous years?
20. Anything you want to say about your sexual life? Is it the same as before?
21. What are the challenges you faced as a breast cancer survivor?
22. Are you very conscious of your body image after treatment? Do you feel incomplete (for mastectomy survivour) or a similar feeling? Does image play an important role among women?
23. Do you have swelling of arms as part of treatment? Does this swelling of your arms hinder you from doing any job?

24. Have you revealed your disease to your relatives /friends? Can you give reasons for that?
25. Have you hidden the fact that you had breast cancer from anyone? If yes, will you please give reasons for doing so
26. Are you worried that your disease might come back? What are your reactions? Did you experience sleeplessness?
27. Do you fear that your daughter will get your disease?
28. What do you do to look after your health? Do you regularly do self-breast examination
29. Have you gained weight? Do you regularly exercise? Do you think that it is important for you?
30. What good changes have happened in your life after being diagnosed with breast cancer?
31. What bad changes have happened in your life after being diagnosed with breast cancer?
32. What do you feel each time you come for a follow-up?
33. How long did you take to visit the doctor after you felt something was wrong before diagnosis?
34. What are the barriers you faced in your help-seeking process?
35. To Whom did you first reveal your symptoms to? Can you please explain the reason?
36. What would you like to convey to a newly diagnosed breast cancer patient?
37. Can you tell me whether you ever morally supported and helped another breast cancer patient cope up with the disease within these 5 years?
38. Can you tell me whether you got to benefit from any treatment schemes of the government?
39. Do you get a pension for cancer patients?
40. What do you understand by the term survivor? Do you consider yourself a survivor?
41. Can you tell me if you are satisfied with coming to the cancer center for a follow-up? Do you feel that it would have been better if the same facility was available at the health center near you?
42. If such a facility is available, would you feel comfortable to avail it?
43. Do you think that sharing your experiences can help other patients in any way?
44. Do you think that this disease and the timely treatment have helped you emerge as a stronger you?
45. Any other details which you feel may be important in this context and would like to add?
46. I thank you for giving your valuable time

B. In-depth interview checklist for survivors with disease at present

1. I understand that you are suffering from a disease now. If you feel that it is ok to talk now, can you tell me when you felt that the disease is coming back? What were the symptoms?
2. Were you aware of the symptoms of recurrence?
3. From whom did you get awareness about that?
4. Have you undergone complete treatment recommended by your doctor previously?
5. Did you take treatment under any other system of medicine?
6. What symptoms do you have now?
7. Are you under treatment now? Please explain the treatment.
8. Are you getting benefits from any treatment schemes of the government? Please explain
9. Does your treatment and symptoms allow you to work now?
10. How does your family manage the financial crisis?
11. Have you adhered to regular follow-up/did you skip or stop follow-up at any point of time?
12. What are the reasons or factors?
13. During your initial diagnosis, did you consult a healthcare worker immediately after you felt something was wrong?
14. What are the barriers you faced in your help seeking process?
15. Looking back do you think there was a delay?
16. What are the reasons you feel for the same?
17. Why do you think the disease has come back?
18. Were you provided with any awareness regarding the signs and symptoms of recurrence by your health care provider? Do you feel that there should be separate clinic/facility for follow up instead of coming to a cancer center?
19. Were you afraid that your disease will come back? Can you please tell me why you felt so
20. Do you ever have sleep related problems?
21. If it is ok for you, can you tell me what thoughts prevent you from sleeping
22. Do you know any other person who has survived breast cancer or who is still fighting with the disease among your circle?
23. Do you think that sharing your experiences can help other patients in any way?
24. Any other details which you feel may be important in this context and would like to add?
25. I thank you for giving your valuable time

A14 In-depth interview checklist for disease-free survivors



1. നിങ്ങളുടെ റെക്കോർഡിനെ അടിസ്ഥാനമാക്കി നിങ്ങളുടെ അവസാനത്തെ ഫോളോ അപ്പ് തീയതി നൽകുമോ? (ലഭ്യമായ ഏതെങ്കിലും റെക്കോർഡിനായി അഭ്യർത്ഥിക്കാം
2. നിങ്ങളുടെ അഭിപ്രായത്തിൽ ഡോക്ടറുടെ നിർദേശപ്രകാരമുള്ള തുടർസന്ദർശനങ്ങൾ / ഫോളോ-അപ്പ് നടത്തിയിരുന്നോ ? അങ്ങനെയാണെങ്കിൽ നിങ്ങൾ എത്ര തവണ ? ദയവായി വിശദീകരിക്കുക
3. തുടർസന്ദർശനങ്ങൾ / ഫോളോ-അപ്പ് നടത്തിയിട്ടില്ലെങ്കിൽ കാരണങ്ങൾ വ്യക്തമാക്കാമോ?
4. നിലവിലെ അസുഖത്തിനുള്ള നിങ്ങളുടെ ചികിത്സയെ അടിസ്ഥാനമാക്കി, നിങ്ങൾ ഇപ്പോൾ ഏതെങ്കിലും മരുന്ന് കഴിക്കുന്നുണ്ടോ?
5. നിങ്ങളുടെ ആരോഗ്യത്തിന്റെ ഇന്നത്തെ അവസ്ഥയെക്കുറിച്ചുള്ള നിങ്ങളുടെ അനുഭവം എന്താണ്? വിശദീകരിക്കാൻ സമയം നൽകുക (വിശദീകരിക്കാൻ ബുദ്ധിമുട്ടുള്ള സാഹചര്യത്തിൽ, ക്ഷീണം, വേദന, അജ്ഞാത ഭയം തുടങ്ങിയ സൂചനകൾ നൽകാം)
6. നിങ്ങൾ ജോലി ചെയ്യാൻ തുടങ്ങിയോ (വീട്ടുജോലികൾ / ശമ്പളമുള്ള ജോലി) .ചികയുക .
7. നിങ്ങളുടെ തൊഴിൽ / ജോലി / പദവി എന്നിവയിൽ എന്തെങ്കിലും മാറ്റം ഉണ്ടായിട്ടുണ്ടോ ? ചികയുക
8. മാറ്റത്തിന് എന്തെങ്കിലും കാരണങ്ങൾ വിശദീകരിക്കാമോ?
9. മുമ്പത്തെപ്പോലെ നിങ്ങളുടെ എല്ലാ ജോലികളും ചെയ്യാൻ നിങ്ങൾക്ക് കഴിയുന്നുണ്ടോ? അതെ എന്നാണ് ഉത്തരമെങ്കിൽ വിശദീകരിക്കുക , ഇല്ലെങ്കിൽ എന്തുകൊണ്ട്?
10. നിങ്ങൾക്ക് മുമ്പ് ഉറക്ക സംബന്ധമായ അസ്വസ്ഥതകൾ ഉണ്ടായിട്ടുണ്ടോ … .. മാസങ്ങൾ / ദിവസങ്ങൾ?
11. നിങ്ങൾക്ക് ഒറ്റപ്പെട്ടുപോയതായി തോന്നുന്നുണ്ടോ? ഉണ്ടെങ്കിൽ, എന്തുകൊണ്ടാണ് നിങ്ങൾക്ക് അങ്ങനെ തോന്നുന്നതെന്ന് വിശദീകരിക്കാമോ?

12. നിങ്ങളുടെ ഇപ്പോഴത്തെ അവസ്ഥയിൽ നിങ്ങൾ സന്തുഷ്ടയാണോ? അല്ലെങ്കിൽ ഈ അവസ്ഥയിലൂടെ കടന്നുപോകുന്നതിനേക്കാൾ മരിക്കുന്നതാണ് നല്ലതെന്നോ ,സമാനമായ ചിന്തകളോ എപ്പോഴെങ്കിലും ഉണ്ടായിട്ടുണ്ടോ ?

13. നിങ്ങൾ ഇപ്പോൾ കൂടുതൽ സജീവമാണോ അതോ ഉൾവലിഞ്ഞതായി തോന്നുന്നുണ്ടോ?

14. ചികിത്സയുടെ ഭാഗമായി മുടി നഷ്ടപ്പെട്ടോ? അപ്പോൾ നിങ്ങളുടെ വികാരങ്ങൾ എന്തായിരുന്നു? നിങ്ങളുടെ മുടി ഇപ്പോൾ വളർന്നിട്ടുണ്ടോ?

15. നിങ്ങളുടെ അയൽക്കാരിൽ നിന്നോ സുഹൃത്തുക്കളിൽ നിന്നോ കുടുംബത്തിൽ നിന്നോ എന്തെങ്കിലും അപമാനം/ മാറ്റിനിറുത്തൽ തുടങ്ങിയവ അനുഭവിച്ചിട്ടുണ്ടോ (ചടങ്ങുകളിൽ പങ്കെടുക്കുമ്പോൾ, മകൾക്കു വിവാഹാലോചന നടക്കുമ്പോൾ തുടങ്ങിയവ) അന്വേഷിക്കുക

16. നിങ്ങളോട് ഇപ്പോൾ നിങ്ങളുടെ മക്കളുടെ മനോഭാവം എന്താണ്? എന്തെങ്കിലും മാറ്റം നിങ്ങൾക്ക് അനുഭവപ്പെടുന്നുണ്ടോ?

17. നിലവിൽ നിങ്ങളുടെ ഭർത്താവിന്റെ മനോഭാവം എന്താണ്? മുൻ വർഷങ്ങളിൽ നിന്നുള്ള മനോഭാവത്തിൽ എന്തെങ്കിലും മാറ്റം ഉണ്ടോ?

18. നിലവിൽ നിങ്ങളോട് നിങ്ങളുടെ കൂട്ടുകാരുടെ മനോഭാവം എന്താണ്? മുൻ വർഷങ്ങളിൽ നിന്നുള്ള മനോഭാവത്തിൽ എന്തെങ്കിലും മാറ്റം ഉണ്ടോ?

19. നിങ്ങളോട് നിങ്ങളുടെ അമ്മായിയപ്പൻറെയും അമ്മായിയമ്മയുടെയും മനോഭാവം എന്താണ്? മുൻ വർഷങ്ങളിൽ നിന്നുള്ള എന്തെങ്കിലും മാറ്റം നിങ്ങൾ ശ്രദ്ധിച്ചിട്ടുണ്ടോ?

20. നിങ്ങളുടെ ലൈംഗിക ജീവിതം എങ്ങനെയുണ്ട്? മുമ്പത്തെപ്പോലെ തന്നെയാണോ?

21. സ്തനാർബുദത്തെ അതിജീവിച്ചയാൾ എന്ന നിലയിൽ നിങ്ങൾ നേരിട്ട വെല്ലുവിളികൾ എന്തൊക്കെയാണ്?

22. ചികിത്സയ്ക്കുശേഷം നിങ്ങളുടെ ശരീരത്തിൽ (പ്രത്യേകിച്ച് സ്തനങ്ങളിൽ)വന്ന മാറ്റങ്ങളെക്കുറിച്ചു നിങ്ങൾ അമിതമായി ബോധവതിയാകാറുണ്ടോ? നിങ്ങൾ അപൂർണ്ണയാണെന്നോ അല്ലെങ്കിൽ സമാനമായ തോന്നൽ ഉണ്ടാകാറുണ്ടോ? സ്ത്രീകൾക്കിടയിൽ ശാരീരിക ഇമേജ് ഒരു പ്രധാന പങ്ക് വഹിക്കുന്നുണ്ടോ?

23. ചികിത്സയുടെ ഭാഗമായി നിങ്ങൾക്ക് കൈകളിൽ നീര് / വീക്കം ഉണ്ടോ? നിങ്ങളുടെ കൈകളുടെ ഈ വീക്കം ഏതെങ്കിലും ജോലി ചെയ്യുന്നതിൽ നിന്ന് നിങ്ങളെ തടസ്സപ്പെടുത്തുന്നുണ്ടോ?

24. നിങ്ങളുടെ രോഗം നിങ്ങളുടെ ബന്ധുക്കളോട് / സുഹൃത്തുക്കളോട് വെളിപ്പെടുത്തിയിട്ടുണ്ടോ? അതിന് കാരണങ്ങൾ പറയാമോ?

25. നിങ്ങൾക്ക് സ്തനാർബുദം ഉണ്ടെന്ന വസ്തുത ആരിൽ നിന്നെങ്കിലും മറച്ചുവെച്ചിട്ടുണ്ടോ? ഉണ്ടെങ്കിൽ, അങ്ങനെ ചെയ്യുന്നതിന് കാരണങ്ങൾ നൽകാമോ?

26. നിങ്ങളുടെ രോഗം തിരിച്ചുവരുമെന്ന് നിങ്ങൾ ഭയപ്പെടുന്നുണ്ടോ? നിങ്ങളുടെ പ്രതികരണങ്ങൾ എന്താണ്? അതാലോചിച്ചു നിങ്ങൾക്ക് ഉറക്കമില്ലായ്മ അനുഭവപ്പെടാറുണ്ടോ?

27. നിങ്ങളുടെ മകൾക്ക് നിങ്ങളുടെ രോഗം വരുമെന്ന് നിങ്ങൾ ഭയപ്പെടുന്നുണ്ടോ?

28. നിങ്ങളുടെ ആരോഗ്യം പരിപാലിക്കാൻ നിങ്ങൾ എന്തുചെയ്യുന്നു? നിങ്ങൾ പതിവായി സ്വയം സ്തന പരിശോധന നടത്തുന്നുണ്ടോ?

29. നിങ്ങളുടെ ശരീരഭാരം വർദ്ധിച്ചിട്ടുണ്ടോ? നിങ്ങൾ പതിവായി വ്യായാമം ചെയ്യുന്നുണ്ടോ? ഇത് നിങ്ങൾക്ക് പ്രധാനമാണെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ?

30. സ്തനാർബുദം കണ്ടെത്തിയതിന് ശേഷം നിങ്ങളുടെ ജീവിതത്തിൽ എന്തെങ്കിലും നല്ല മാറ്റങ്ങൾ സംഭവിച്ചിട്ടുണ്ടോ?

31. സ്തനാർബുദം കണ്ടെത്തിയതിന് ശേഷം നിങ്ങളുടെ ജീവിതത്തിൽ എന്തെങ്കിലും മോശം മാറ്റങ്ങൾ സംഭവിച്ചിട്ടുണ്ടോ?

32. ഫോളോ അപ്പിനായി ഓരോ തവണ വരുമ്പോഴും നിങ്ങൾക്ക് എന്തു തോന്നുന്നു?

33.രോഗനിർണയത്തിന് മുമ്പ് എന്തോ കുഴപ്പമുണ്ടെന്ന് തോന്നിയതിന് ശേഷം ഡോക്ടറെ കാണാൻ എത്ര സമയമെടുത്തു

34. ഈ പ്രക്രിയയിൽ നിങ്ങൾ നേരിട്ട തടസ്സങ്ങൾ/ ബുദ്ധിമുട്ടുകൾ /പ്രതിബന്ധങ്ങൾ എന്തൊക്കെയാണ്?

35. നിങ്ങളുടെ ലക്ഷണങ്ങൾ നിങ്ങൾ ആരോടാണ് ആദ്യം വെളിപ്പെടുത്തിയത്? കാരണം വിശദീകരിക്കാമോ?

36. പുതുതായി രോഗനിർണയം നടത്തിയ സ്തനാർബുദ രോഗിയോട് നിങ്ങൾ എന്ത് കാര്യങ്ങളാണ് പറയാൻ ആഗ്രഹിക്കുന്നത്?

37. ഈ 5 വർഷത്തിനുള്ളിൽ നിങ്ങൾ എപ്പോഴെങ്കിലും മറ്റൊരു സ്തനാർബുദ രോഗിയെ ധാർമ്മികമായി പിന്തുണയ്ക്കുകയും സഹായിക്കുകയും ചെയ്തിട്ടുണ്ടോ എന്ന് പറയാമോ?

38. സർക്കാരിന്റെ ഏതെങ്കിലും ചികിത്സാ പദ്ധതികളിൽ നിന്ന് നിങ്ങൾക്ക് ആനുകൂല്യം ലഭിച്ചോ എന്ന് പറയാമോ?

39. കാൻസർ രോഗികൾക്കായുള്ള പെൻഷൻ ,നിങ്ങൾക്ക് ലഭിക്കുന്നുണ്ടോ?

40. അതിജീവിച്ചയാൾ എന്ന പദം കൊണ്ട് നിങ്ങൾ എന്താണ് മനസ്സിലാക്കുന്നത്? നിങ്ങൾ സ്വയം ഒരു അതിജീവനക്കാരനായി കരുതുന്നുണ്ടോ?
41. ഫോളോ അപ്പിനായി കാൻസർ സെന്‌ററിലേക്ക് വരുന്നതിൽ നിങ്ങൾ സംതൃപ്തയാണോ എന്ന് പറയാമോ? നിങ്ങളുടെ അടുത്തുള്ള ആരോഗ്യ കേന്ദ്രത്തിലും ഇതേ സൗകര്യം ലഭ്യമായിരുന്നെങ്കിൽ നന്നായിരുന്നുവെന്ന് നിങ്ങൾക്ക് തോന്നുന്നുണ്ടോ?
42. അത്തരമൊരു സൗകര്യം ലഭ്യമാണെങ്കിൽ നിങ്ങൾ അത് പ്രയോജനപ്പെടുത്തുമോ?
43. നിങ്ങളുടെ അനുഭവങ്ങൾ പങ്കുവയ്ക്കുന്നത് മറ്റ് രോഗികളെ ഏതെങ്കിലും വിധത്തിൽ സഹായിക്കുമെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ?
44. ഈ രോഗവും സമയബന്ധിതമായ ചികിത്സയും നിങ്ങളെ കൂടുതൽ കരുത്തുള്ളവളായി ഉയർന്നു വരാൻ സഹായിച്ചുവെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ?
45.ഈ വിഷയം സംബന്ധിച്ച മറ്റെന്തെങ്കിലും കാര്യം നിങ്ങൾ ഈ അവസരത്തിൽ പങ്കുവയ്ക്കാൻ ആഗ്രഹിക്കുന്നുണ്ടോ?
46. നിങ്ങളുടെ വിലയേറിയ സമയം നൽകിയതിന് ഞാൻ നന്ദി പറയുന്നു

B. In-depth interview checklist for survivors with disease at present

1. നിങ്ങൾ ഇപ്പോൾ രോഗബാധിതയാണെന്ന് ഞാൻ മനസ്സിലാക്കുന്നു. ഇപ്പോൾ സംസാരിക്കുന്നത് ശരിയാണെന്ന് നിങ്ങൾക്ക് തോന്നുന്നുവെങ്കിൽ, രോഗം വീണ്ടും വരുന്നുവെന്ന് നിങ്ങൾക്ക് തോന്നിയതെപ്പോൾ എന്ന് എന്നോട് പറയാമോ? എന്തായിരുന്നു ലക്ഷണങ്ങൾ?

2. രോഗം വീണ്ടും വരുന്നതിന്റെ/ പടരുന്നതിന്റെ ലക്ഷണങ്ങളെക്കുറിച്ച് നിങ്ങൾക്കറിയാമായിരുന്നോ? 3.ആരാണ് ശ്രദ്ധിക്കേണ്ട ലക്ഷണങ്ങളെ കുറിച്ചു പറഞ്ഞു തന്നത്?

4.മുമ്പ് ഡോക്ടർ ശുപാർശ ചെയ്ത പൂർണ്ണ ചികിത്സയ്ക്ക് നിങ്ങൾ വിധേയയായിട്ടുണ്ടോ?

5. മറ്റേതെങ്കിലും വൈദ്യശാസ്ത്ര സമ്പ്രദായത്തിന് കീഴിൽ നിങ്ങൾ ചികിത്സയ്ക്ക് വിധേയയായിരുന്നോ?

6. നിങ്ങൾക്ക് ഇപ്പോൾ എന്ത് ലക്ഷണങ്ങളാണുള്ളത്?

7. നിങ്ങൾ ഇപ്പോൾ ചികിത്സയിലാണോ? എന്ത് ചികിത്സയാണെന്നു വിശദീകരിക്കാമോ?

8. സർക്കാരിന്റെ ഏതെങ്കിലും ചികിത്സാ പദ്ധതികളിൽ നിന്ന് നിങ്ങൾക്ക് ആനുകൂല്യം ലഭിക്കുന്നുണ്ടോ എന്ന് വിശദീകരിക്കാമോ?

9. നിങ്ങളുടെ ചികിത്സയും ലക്ഷണങ്ങളും കാരണം ഇപ്പോൾ ജോലിക്ക് പോകാൻ നിങ്ങൾക്ക് കഴിയുന്നുണ്ടോ ?

10. രോഗം മൂലമുള്ള സാമ്പത്തിക പ്രതിസന്ധി നിങ്ങളുടെ കുടുംബം എങ്ങനെ കൈകാര്യം ചെയ്യുന്നു?

11. നിങ്ങളുടെ അഭിപ്രായത്തിൽ ഡോക്ടറുടെ നിർദേശപ്രകാരമുള്ള തുടർസന്ദർശനങ്ങൾ / ഫോളോ-അപ്പ് നടത്തിയിരുന്നോ ? ഏതെങ്കിലും സമയത്തു നിങ്ങൾ ഫോളോ അപ്പ് ഒഴിവാക്കുകയോ നിർത്തുകയോ ചെയ്തിട്ടുണ്ടോ?

12. തുടർസന്ദർശനങ്ങൾ / ഫോളോ-അപ്പ് നടത്തിയിട്ടില്ലെങ്കിൽ കാരണങ്ങൾ അല്ലെങ്കിൽ ഘടകങ്ങൾ വ്യക്തമാക്കാമോ?

13. നിങ്ങളുടെ പ്രാഥമിക രോഗനിർണയ സമയത്ത്, എന്തോ കുഴപ്പമുണ്ടെന്ന് തോന്നിയതിന് ശേഷം ഉടൻ നിങ്ങൾ ഒരു ആരോഗ്യ പ്രവർത്തകനെ സമീപിച്ചോ?

14.ഈ പ്രക്രിയയിൽ നിങ്ങൾ നേരിട്ട തടസ്സങ്ങൾ/ ബുദ്ധിമുട്ടുകൾ /പ്രതിബന്ധങ്ങൾ എന്തൊക്കെയാണ്?

15. തിരിഞ്ഞുനോക്കുമ്പോൾ കാലതാമസമുണ്ടെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ?

16. ഇതിനുള്ള കാരണങ്ങൾ എന്തൊക്കെയാണ് എന്നാണ് നിങ്ങൾ കരുതുന്നത്?

17. എന്തുകൊണ്ടാണ് രോഗം തിരിച്ചുവന്നത് എന്നാണ് നിങ്ങൾ കരുതുന്നത്?

18. ആരോഗ്യ പ്രവർത്തക രോഗം വീണ്ടും വരുന്നതിന്റെ /പടരുന്നതിന്റെ ലക്ഷണങ്ങളെയും കുറിച്ച് എന്തെങ്കിലും അവബോധം നൽകിയിട്ടുണ്ടോ? ഒരു കാൻസർ സെന്ററിലേക്ക് വരുന്നതിനുപകരം ഫോളോ അപ്പിനായി പ്രത്യേക ക്ലിനിക് / സൗകര്യം ഉണ്ടായിരിക്കണമെന്ന് നിങ്ങൾക്ക് തോന്നുന്നുണ്ടോ?

19. നിങ്ങളുടെ രോഗം തിരിച്ചുവരുമെന്ന് നിങ്ങൾ ഭയപ്പെട്ടിരുന്നോ? നിങ്ങളുടെ പ്രതികരണങ്ങൾ ?

20. നിങ്ങൾക്ക് ഉറക്കമില്ലായ്മ അനുഭവപ്പെടാറുണ്ടോ?

21. ഉറക്കത്തിൽ നിന്ന് നിങ്ങളെ തടയുന്ന ചിന്തകൾ എന്താണെന്ന് എന്നോട് പറയാം

22. നിങ്ങളുടെ (സുഹൃത്തുക്കൾക്കിടയിൽ /ബന്ധുക്കൾക്കിടയിൽ) സ്തനാർബുദത്തെ അതിജീവിച്ച അല്ലെങ്കിൽ ഇപ്പോഴും രോഗവുമായി പോരാടുന്ന മറ്റാരെയെങ്കിലും നിങ്ങൾക്ക് അറിയാമോ?

23. നിങ്ങളുടെ അനുഭവങ്ങൾ പങ്കുവയ്ക്കുന്നത് മറ്റ് രോഗികളെ എതെങ്കിലും വിധത്തിൽ സഹായിക്കുമെന്ന് നിങ്ങൾ കരുതുന്നുണ്ടോ?

24. ഈ വിഷയം സംബന്ധിച്ച മറ്റെന്തെങ്കിലും കാര്യം നിങ്ങൾ ഈ അവസരത്തിൽ പങ്കുവയ്ക്കാൻ ആഗ്രഹിക്കുന്നുണ്ടോ?

25. നിങ്ങളുടെ വിലയേറിയ സമയം നൽകിയതിന് ഞാൻ നന്ദി പറയുന്നു.

A15

Checklist for reviewing policy documents related to breast cancer control

a) Key institutions, organizations, and departments involved in cancer/breast cancer control.
b) Functions and responsibilities of key stakeholders involved in cancer/breast cancer control.
c) Discussion on early diagnosis
d) Key persons or functionaries involved in breast cancer control and their roles.
e) Goals and objectives laid down with reference to breast cancer control.
f) Context of discussion on breast cancer
g) Administrative and technical content
h) Extend of participation.
i) Guidelines for follow-up mentioned
j) Mention on survivorship care

Errata

Annexure 13

Checklist for in-depth interviews of survivors for survivor experiences

A. In-depth interview checklist for disease-free survivors

Question no 31

What bad changes have happened in your life after being diagnosed with breast cancer?

This question is now reworded as:

31. Can you recall any negative changes/events that occurred in your life after being diagnosed with breast cancer?”