

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 its 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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