



## Perspective

### Breast cancer survivorship in India

Treatment is the process of administration of medical management with the intent to cure or palliate. Survivorship runs parallel to treatment and should be accompanied by better living. Survivorship, when dealing with the treatment of cancer patients, refers to the 'health and life of a person with cancer post diagnosis until the end of life', as defined by the National Cancer Institute<sup>1</sup>. This definition includes the physical, social, mental and financial effects of cancer faced by the patient beyond the diagnosis and completion of treatment. It also pertains to issues related to follow up after completion of treatment, the possibility of recurrences, second cancers, and quality of life (QOL)<sup>2</sup>.

The concept of survivorship related to cancer patients was introduced into the Western world, early on, between the sixth and seventh decades of the 20<sup>th</sup> century, when the development of effective treatments led to improved survival from a hitherto deadly disease<sup>3</sup>. A cancer patient is a survivor, from the day of diagnosis of a potentially fatal illness, through the myriad of treatments, many of which are as toxic as the disease itself; and after treatment is complete, going on to live as normal a life as possible. The concept also extends to the patients' caregivers and family members; as they too are affected by the diagnosis, periods of prolonged treatment and intensive nursing care, as well as the short-term and long-term side effects of the treatment experienced by the patient<sup>3</sup>.

#### Strengthening a survivorship programme

Survivorship programmes can be strengthened in various ways. Some of these are:

*Patient empowerment:* Cancer treatment follows a multi-disciplinary approach. Patients are required to consult/undergo treatment from surgeons, medical oncologists, radiation oncologists, psychologists, physiotherapists, geneticists, etc. However, making the

patient and the caregiver a part of the team allows them to better understand the treatment options and maintain a sense of control.

*Psycho-education:* This can help survivors relearn behavioural skills in order to adjust to the disease and improve patient adherence to treatment. This can be done individually or in a group.

*Support groups:* These bring together individuals who share a similar problem or disease. It is a forum where information is exchanged and support is shared to help cope or overcome distress and emotional discomfort.

*Survivorship programmes:* These programmes provide services that help cancer survivors live well after cancer treatment. The programme creates a personalized plan from diagnosis to follow up care to help cope with the physical, emotional and social effects of cancer and its treatment. These programmes often act as advocates for patient's rights.

#### Breast cancer survivorship

New challenges for patients of breast cancer begin after the treatment is complete. They venture in to finding, what is commonly referred to as their 'new normal'. Life for survivors is never the same again, be it physically, mentally and socially. The first year post-treatment has been seen to be the hardest. Survivors often grapple with fatigue, neuropathy and cognitive impairment related to post-chemotherapy side-effects. Some patients also suffer from depression and anxiety, along with an omnipresent fear of relapse. A pervasive feeling of alienation from society and difficulty in re-adjusting to conventional social norms are commonly seen among breast cancer survivors. The traditional surveillance model used for breast cancer survivors is focussed more on the physical aspects and early detection of recurrence, ignoring the psychological and emotional aspects of care<sup>4</sup>. This model reportedly saw survivors undergoing unnecessary and excessive

testing at times, with a large variation in the quantum of care provided by the physicians who were following up these patients<sup>5</sup>.

In December 2015, the American Cancer Society published guidelines pertaining to breast cancer survivorship<sup>6</sup> which described the long-term care of patients who had completed treatment for breast cancer. It included recommendations for screening of new and recurrent breast cancers, management of treatment-related side effects and lifestyle modifications to reduce the risk for second cancers. Useful interventions, such as psychological counselling, nutritional advice, physical activity and measures to reduce stress were also highlighted in the guidelines.

Survivorship guidelines and programmes can be formulated to suit the local demographic, as social norms and cultures vary greatly between different world populations<sup>7</sup>. The needs during survivorship vary according to the country, with the local healthcare establishments and teams of clinicians playing a vital role. Cultural issues and socio-economic status are known to influence the ability to execute timely follow up and survivorship care of breast cancer patients, after medical treatment of the disease is completed. While guidelines are important, it is imperative to be able to have an open communication with the treating team of oncologists, at any point during the survivorship period.

In India, a diagnosis of cancer is accompanied by cultural and social stigma, familial distancing, and often, social isolation. Patients therefore need to cope with both: the side effects of the treatment, as well as the psycho-social stigma perceived about their diagnosis.

A consensus document released in 2017, for the management of breast cancer was an effort in this direction, however, the goals of survivorship during follow up mentioned need to be elaborated upon taking into consideration the issues pertaining to timely deliver of appropriate treatment to our breast cancer patients, and their survivorship needs<sup>8</sup>.

### **Onus of breast cancer survivorship programmes in India**

Most tertiary care hospitals in India now have fully equipped comprehensive cancer treatment units, including surgical, medical and radiation oncology. Breast cancer makes up approximately 15-20 per cent of the workload across Oncology departments<sup>9</sup>. These

hospitals run regular Breast cancer support group meetings, which encourage patients to meet regularly and share their experiences. An advantage of these support groups is that old patients and survivors meet new patients that are undergoing treatment guiding them into survivorship. Often, non-government organisations partner with such hospitals and their volunteers conduct these support group meetings with topics ranging from diet, exercise, lymphedema prevention and therapy; to fun activities including yoga and dance therapy.

### **Difference in perspectives on breast cancer survivorship**

There seems to be a difference in perspective between medical professionals and patients when it comes to survivorship. While clinicians are more interested in addressing the side effects of the treatment, looking for signs and symptoms of a relapse, or second malignancies; a cancer survivor is more concerned with the day-to-day discomfort, which includes hot flashes from hormonal treatment, weight gain, paraesthesia due to peripheral neuropathy and difficulty in concentration or cognitive disturbances. Many also suffer from a lack of confidence. Most would want to forget the trauma of the diagnosis of cancer, the multiple lines of treatment and look forward to moving on to a different, more positive life situation. Understanding that these differences exist and working with them are key to developing a strong and effective survivorship programme.

One of the efforts towards building such a programme has been the Indian Breast Cancer Survivors Conference (<https://www.wci.co.in/our-activities/survivors-conference>), which is an annual event. The first such meeting was held in 2012 in Pune, India (<https://www.wci.co.in/our-activities/survivors-conference>) which brought together breast cancer survivors from several States of India, including survivors from over five cities across the State of Maharashtra. During the Annual Indian Breast Cancer Survivors Conference held in 2017, a three page bilingual survey was filled out by 190 survivors<sup>10</sup>. The filling of the survey questionnaire was voluntary and due consent was taken from all participants. Of the 190 respondents, only 126 responses were analyzed. Efforts such as these may help in devising a better survivorship programme.

### **Breast cancer survivorship in India**

There is a paucity of data available related to breast cancer survivorship in India.

A pilot study<sup>11</sup> on the physical, social, psychological and economic issues of Indian adult cancer survivors concluded that a majority of survivors experienced fatigue (52%), and loss of appetite (27%). The study also reported that a high percentage of respondents had moderate-to-severe financial setbacks, receiving no financial assistance during and after treatments. In the psychological framework, social anxiety, post-traumatic stress disorder and depression figured commonly. It further concluded that there is a need to address these issues particularly in the context of developing countries where resources and workforce are limited.

A more recent hospital-based cross-sectional study of 230 survivors looked at the QOL issues among North Indian breast cancer survivors<sup>12</sup>, concluded the most significant factors that impacted QOL in a negative manner were emotional distress, cancer-related fatigue and premature menopause leading to sexual dysfunction.

Both these studies highlight the fact that emotional health and psychosocial aspects of survivorship are important and play a large part in determining QOL post breast cancer treatment. While these factors vary according to the cultural and social conditions prevalent in different geographic locations in the world, it seems to be a common theme uniting breast cancer survivors globally. Some of the cancer survivorship programmes that are available to patients and caregivers worldwide are included in the Annexure.

Overall, with newer and more effective treatments available, more women are surviving breast cancer and looking forward to a longer life. Survivorship begins with the diagnosis of breast cancer and continues even after treatment ends, right till the end of life. Thus, longevity is not enough and the QOL is equally, if not more, important. Follow up visits must include all aspects of wellness. Apart from physical health, this includes the social, emotional and psychological needs of the survivor. It is time to build a strong survivorship programme for the one million-plus breast cancer survivors living in India. This is a need of the hour.

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## **Annexure**

### **International Survivorship Programmes**

#### **BUILDING A SURVIVORSHIP PROGRAMME: ASCO**

A series of resources aimed at assisting oncologists and other clinicians with implementing quality survivorship programmes within their practices. Includes explanations of the different models of care delivery and potential barriers to implementation, and assists with the identification of existing and needed resources.

#### **CANCER SURVIVORSHIP PROGRAMME: UCSF**

The Cancer Survivorship Programme is specifically designed for UCSF patients who have completed their initial treatment for cancer. At this point, patients find they need different forms of support than while they were in active treatment.

#### **SURVIVORSHIP PROGRAMME: UNIVERSITY OF KANSAS MEDICAL CENTRE**

Their survivorship programme is designed to consider the physical, psychosocial and economic sequelae of cancer by focussing on health care delivery, access, follow up care and preventing and controlling side effects to optimise quality of life, providing a knowledge base for follow up care and surveillance after the completion of treatment.