



## Challenges and Opportunities for Breast Cancer Survivorship Care in India during Covid-19 Pandemic

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### ABSTRACT

Breast cancer survivors faced challenges even during before COVID-19 era. During the pandemic era of COVID-19, breast cancer survivors represent a vulnerable population to various health problems, Psych-social disturbances and long term morbid consequences. The Indian Health care system is not fully prepared to deliver appropriate and quality care to non-COVID patients. The structural barriers to care are results in a pitiable condition, particularly for survivors living in rural areas. We reviewed the literature on cancer survivorship, Indian resources available and the challenges faced by breast cancer survivors. The current guidelines, standard operating procedures (SOP), Health care policies by Indian central government, state public health departments, non-government organisations, cancer treatment and research centres were analysed by data abstraction sheet. Multiple health governing agencies displayed general recommendations to modify the delivery of health care to minimise patient exposure to the virus. Minimal and limited health care resources are available for Breast Cancer survivors. As this pandemic continues the scientific evidence are expected regarding more specific recommendations and guidelines for survivorship care. Immediate efforts are required for addressing the needs of breast cancer survivors at present the development and implementation of policies for survivorship care. It is essential to implement interventions and policy for breast cancer survivors to mitigate the effects of this pandemic.



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### INTRODUCTION

The COVID-19 is globally one of the largest and deadliest pandemics of the 21st century. India is facing the worst pandemics since the post-independence. The COVID-19 pandemic has adversely affected the world. This pandemic resulted in disruption of the day to day life of cancer survivors. In the current situation, anyone can get COVID-19, people already having cancer and cancer survivors may be at greater risk of health complications because cancer and cancer treatment can contribute to weakened immune systems. These individuals and their healthcare providers are grappling with difficult questions

about how to navigate their care, including whether it is safe to continue their treatment, whether their care will be de-prioritised in a healthcare system that is strained by COVID-19 and what precautions they may take to mitigate the risk of contracting the virus. Cancer survivors, for the most part, have seen their routine tests postponed and follow-up visits delivered via phone or video. The impacts of COVID-19 consist of multiple obstacles for those who are undergoing the treatment such as non-availability of primary care oncologists, limited patient appointment if available, scarcity hospital beds and drugs, non-availability transport facilities due to lockdown, burdened health care services. Much work has been done over the past several decades about government-run medical insurance schemes, cost-effective treatment of cancer treatment. The healthcare system needs to be continuously upgraded to receive high-quality and effective cancer survivorship care. Globally, India ranks third in overall cancer patients; this makes cancer the second most common cause of death in India. Data From the cancer registries in India, a total of nearly 1.4 million cancer cases were estimated for the year 2015, and it is predicted that, without any control measures, this figure would increase to 1.74 million cases for the year 2020 ([National Cancer Registry Programme \(NCRP\), 2016](#)). Globally, non-communicable diseases (NCDs) accounted for 71% of total deaths. In India, NCDs were estimated to account for 63% of all deaths, and cancer was one of the leading causes (9%) ([Mathur et al., 2020](#)).

On the other hand, those who have finished treatment, and those who are now cancer survivors are also facing multiple problems. Health-related stigma is increasingly recognised as a factor influencing health promotion, disease prevention, and control ([Global Cancer Observatory, 2020](#)). A recent survey conducted by the World Health Organization revealed that 94% of countries the health care professionals and paramedical staff working in the area of non-communicable diseases (NCDs) were partially or fully posted to support COVID-19. Rehabilitation services have been seriously affected by almost two-thirds (63%) of the countries. In 20% of countries, one of the main reasons for discontinuing services was a shortage of medicines, diagnostics and other technologies ([Nekhlyudov et al., 2020](#)). Various Indian organisations Government and non-government have provided the cancer survivorship care community for patients, survivors and healthcare providers recommendations regarding COVID-19 (Table 1). Many health care organisations from the past several decades helping breast cancer sur-

vivors. A mainstream effort of the health care system is to provide care for the pandemic. The Health care system is not fully prepared to deliver appropriate and quality care to non-COVID patients. The structural barriers to care are results in a pitiable condition, particularly for survivors living in rural areas.

Based on current evidence, More severe manifestations are noted in those who are elderly and have pre-existing co-morbidities, medical conditions like diabetes mellitus, chronic kidney disease, including cancer, may be at higher risk for life-threatening medical complications ([Yu et al., 2020](#); [Liang et al., 2020](#)).

In this current scenario, the limited evidence regarding the impact of COVID-19 on cancer survivors. As this pandemic continues the scientific evidence are expected regarding more specific recommendations and guidelines for survivorship care. Immediate efforts are required for addressing the needs of breast cancer survivors at present, the development and implementation of policies for survivorship care. It is essential to implement interventions and policy for breast cancer survivors to mitigate the effects of this pandemic.

## METHODS

The current guidelines, standard operating procedures (SOP), Health care policies by Indian central government, state public health departments, non-government organisations, cancer treatment and research centres were analysed by data abstraction sheet. The following main concerns of breast cancer survivors were considered. These concerns are mainly associated with survivorship care and if neglected due to COVID-19 pandemic can cause a significant downward spiral, reducing physical functioning and worsening the symptoms related to fatigue, which increases the risk of developing other diseases and reduces life expectancy in this population.

**The current status of health care resources, Opportunities for health care system and challenges faced by breast cancer survivors were analysed.**

**What is the impact of the covid-19 pandemic on the general health of breast cancer survivors**

Reviewing the current data, COVID-19 gravely affects the older and persons with pre-existing co-morbidities, including cancer, may be at higher risk for severe and life-threatening medical complications. The majority of breast cancer survivors who are aged 65 and older with pre-existing

co-morbidities, like diabetes, hypertension, COPD, Ischemic heart disease, renal failure, Lung fibrosis, major post-operative surgeries (heart, spine, brain etc.) with ongoing late and long-term effects, those who remain immunosuppressed post-treatment, or those who continue to receive immunosuppressive therapy, cancer survivors are at risk for COVID-19 and its potential complications. Physiological changes in breast cancer survivors are enumerated in Table 2.

### **What are specific health needs for breast cancer survivors to stay healthy**

The implementation of high-quality survivorship care can be challenging, including services of multi-speciality and multidisciplinary healthcare professionals with the necessary expertise. Allocation of high-quality patient-centred care is continuously required for the elimination of healthcare disparities in breast cancer survivors. Considering all the current resources (Table 1), the information available is general and is not useful for specific health needs (Table 3) for breast cancer survivors. The resources are available in the English language; this is again the main barrier for understanding to a large number of breast cancer survivors (Karliner *et al.*, 2011). The breast cancer survivors from the low-income group, living in remote areas with no mobile and internet facilities are not getting this information. These health needs must be considered; otherwise, breast cancer survivors condition may get worsened with time and become difficult to recover. Specific health needs for breast cancer survivors to stay healthy are mentioned in Table 3

### **What are the physical and psychosocial challenges for breast cancer survivors during COVID 19 Pandemic**

The Physical and psychosocial challenges for breast cancer survivors are enumerated in Table 4. The physical and psychosocial impact of the pandemic may also directly affect this population. Breast Cancer survivors have been described in the past as some having unique physical and psychosocial needs related to physical functioning, anxiety, depression, fear of recurrences as well as family, interpersonal relationship, financial problems, and employment (Reed *et al.*, 2020; Carrera *et al.*, 2018; Aaronson *et al.*, 2014). Cancer-related distress can be expected to dissipate with time for the majority of individuals diagnosed with breast cancer. But this pandemic is exacerbating the psychosocial distress. The stress related to this pandemic may increase other treatment-related effects reported among cancer survivors. This is particularly challenging as changes have been very rapid

and ongoing. The COVID-19-driven lockdown of non-essential services and diverted focus of health-care resources may also increase anxiety and confusion among cancer survivors. Survivors who are receiving ongoing cancer treatment may struggle with tough challenges about the availability of oncologists, treatment facilities, diagnostic services, transport and other services while perhaps also feeling anxious about the potential threats of getting infected with COVID-19 in clinical facilities. Due to ongoing concerns about the availability of health-care resources, ICU beds, Oxygen support, ventilators, and intensivists, cancer survivors may fear for possible prioritisation of their health needs (Sokol, 2020).

### **What resources are available to address the concerns of breast cancer survivors during a covid-19 pandemic**

In this current scenario, not many adequate resources are available. The limited e-content can be useful for certain urban and financially strong cancer survivors. The need of the hour is utilisation and strengthening of available resources. The continuous up-gradation of resources is must counter ongoing and future challenges. The cancer survivor support groups need to be formed and made equipped on a war footing. Government hospitals and private hospitals must work jointly for this purpose. Cancer support groups must widen their horizon, and it must reach up to Primary health centres to trace cancer survivors and provide the necessary help.

Once the Primary health centre level network of support groups is developed, it will of great value for future endeavours. This is one of the ample opportunity out of this challenge. Though challenging in current time, clinicians must continue to offer ongoing contact with these patients by using telemedicine resources, review their symptoms, and provide reassurances needed through virtual health platforms, including the existing mobile applications that are currently available. There may also be many opportunities to expand remote monitoring of patient-reported outcomes. (Basch *et al.*, 2016; Denis *et al.*, 2019) and pave the way for survivors to become more engaged and activated (Butow *et al.*, 2018). The use of Information and Communication Technology will make survivorship care cost-effective and time-saving. Clinicians can help by acknowledging and normalising increased levels of anxiety and fear of recurrence and providing appropriate psychosocial referrals when severe (Hanna *et al.*, 2020). The number of cancer survivors who are members of underserved groups is growing,

with members of racial and ethnic minorities predicted to increase significantly by 2030 (Smith *et al.*, 2009). Cancer contributes to poverty and impedes development. Diseases like cancer are a leading cause of so-called catastrophic health expenditure. This is especially true in low- and middle-income countries, where most people rely on out-of-pocket payments for health care.

Survivorship care must be focused to maximise health and well-being, by using survivor-centric strategies to monitor for cancer recurrence, side effects, and overall outcomes. Opportunities for Resources that must be made available to address the concerns of breast cancer survivors during a covid-19 pandemic are illustrated in Table 5.

Many breast cancer patients will have an uneventful recovery from their course of treatments, while still, significant patients experience severe physical and psychosocial sequelae. Health care professionals and paramedical support staff must be prepared to educate women and their families about the most common issues they are likely to experience, and to address each woman's specific problems, to enhance overall recovery, improve physical functioning, and maximise adherence to recommended treatments and survivorship care.

#### **Different community-based models of survivorship care**

The efforts must be made to design and implement self-help strategies and exercise-based intervention model for breast cancer survivors within the socio-cultural context of India.

#### **DISCUSSION**

COVID-19 has almost totally affected all the horizons of survivorship care. This pandemic has forced all of us to change our lives overnight. It has brought a collective sense of insecurity, lack of control over daily health routine and fear of the unknown feelings somewhat very familiar to those who have lived through cancer.

Many survivorship care planning visits were cancelled. Perhaps these steps may be appropriate considering the health threats of a crisis. Cancer survivors can experience helplessness, persistent psychological stress, and difficulties managing associated co-morbidities. However, it is essential to note that it may also create opportunities for various innovations in the healthcare delivery system. These can be appropriately managed with particular efforts on a war footing. It is necessary to prevent loss of breast cancer survivors during this transition. Among breast cancer survivors, not each every

woman requires strict follow-up, but how do we decide who does require it? And what is the best way of follow-up care? Breast Cancer survivors face significant challenges compared with the normal population, and many of these are challenges likely to be exaggerated in the context of the current pandemic. They are more likely to develop chronic diseases such as cardiovascular disease, metabolic syndromes, decreased exercise tolerance, obesity, chronic pain and depression. They may not maintain healthy lifestyle recommendations and may find this maintenance problematical in the context of lockdown, restrictions imposed, Physical and social distancing. They are more likely to be unemployed and under financial strain. These concerns of breast cancer survivors in India are neglected during this pandemic. Now for their survival policymakers and researchers must identify effective exercise strategies and help to standardise survivorship plan of care and address physical functioning impairments. In low-income countries breast cancer survivors are worried about their ability to afford necessary household expenses; in such cases, survivorship care becomes neglected.

This COVID-19 pandemic has created opportunities for the rapid implementation of technology that is useful for safe contact. In the past, despite its advantages, telemedicine faced many barriers from both the sides and technical problems to its successful implementation (Garg *et al.*, 2018). During the COVID-19 crisis, telemedicine approaches are among the only available options for communication. It has promoted for rapid implementation in most of the populations. Telemedicine ranges from simple patient health portal messages to relieve triage phone lines well-planned e-consultation, to telephone- or video-based virtual follow-up and advice.

Considering its advantages, many challenges remain, including (1) training breast cancer survivors and healthcare professionals to participate in telemedicine visits in this crisis, (2) irregular/unequal internet broadband and android mobile access, and (3) relatively low levels of familiarity with patient health web-portals on the part of many survivors and others (Johnson *et al.*, 2020). (4) socio-cultural context of India (5) Financial problems for purchase of android technology mobile phone.

Again this pandemic presents a unique opportunity to test the feasibility of applying e-health procedures for breast cancer survivors on a much larger and more rapidly deployed scale than previously anticipated. In India, for breast cancer survivors Quali-



**Table 1: Selected COVID-19 Indian resources for cancer patients, survivors and healthcare providers**

S. No.	Central and State Government agencies
1.	Government of India Ministry of Health and Family Welfare
2.	National Programme for Prevention and Control of Cancer, Diabets, Cardiovascular Diseases and Stroke (NPCDCS)
3.	National Cancer Control Programme (NCCP)
4.	National Institute of Cancer Prevention and Research (NICPR)
5.	Government Medical institutions and District hospitals
6.	National Cancer Registry Programme
7.	UICC member organisations: India
8.	WHO India
	<b>Trusts and Non-Government organisations</b>
9.	Tata Trusts
10.	Indian Cancer Society
11.	Cancer Aid and Research Foundation
12.	Cancer Patients Aid Association
13.	Association of Gynecologic Oncologists of India
14.	Association of Radiation Oncologists of India
15.	Indian Association of Surgical Oncology
16.	Indian Cooperative Oncology Network
17.	Charutar Arogya Mandal
18.	St. Jude India's Child Care Center
19.	Karunashraya
20.	Cuddles Foundation
21.	DEAN Foundation, Hospice and Palliative Care Centre
22.	Grace Cancer Foundation
23.	Sanjeevani Life Beyond Cancer
24.	Swastava Cancer Care
25.	Global Cancer Concern India (GCCCI)
26.	CanKid

**Table 2: Physiological changes in breast cancer survivors**

S. No.	Changes
1.	↓ Muscle Mass
2.	↓ Decreased Muscle Strength/Power
3.	↓ Pulmonary Function
4.	↓ Cardiac Function
5.	↓ Bone Health
6.	↓ Immune Function
7.	↓ Decreased Exercise/Physical Activity
8.	↑ Lymphedema
9.	↓ Quality Of Life (multiple domains)
10.	↑ Fat Mass
11.	↑ Body Weight or Body Mass Index
12.	↑ Inflammation
13.	↑ Trauma and Scarring
14.	↑ Post-operative myofascial dysfunctions ( <a href="#">Jare et al., 2019</a> ; <a href="#">Jaju and Shinde, 2019</a> ; <a href="#">Alande et al., 2017</a> )

**Table 3: Specific health needs for breast cancer survivors to stay healthy**

S. No.	Treatment for Breast Cancer
1.	Regular follow up and medical check-up
2.	Availability and supply of life-saving drugs like antihypertensive, antiplatelet etc
3.	Availability of beds in case of a health emergency
4.	Access to multi-speciality and multidisciplinary healthcare professionals
5.	Regular involvement in breast cancer support group
6.	Availability of recommended diet
7.	Regular follow up with Physiotherapist
8.	Access to facilities for exercise and physical fitness
9.	Access to meditation and yoga facilities ( <a href="#">Aronson et al., 2014</a> ; <a href="#">Sapkota et al., 2016</a> )

**Table 4: Physical and psychosocial challenges for breast cancer survivors**

Depression	Musculoskeletal problems
Physical symptoms such as fatigue, insomnia, lack of appetite	General aches and pain
Body image disruption	Arthralgias, myalgias, muscle stiffness
Treatment-related anxieties	lymphedema, neuropathy, skin rashes or toxicity
Depression	Weight problems- Weight gain
Feelings of vulnerability	Arm problems- A decreased range of motion of the affected arm, Arm swelling
Existential concerns regarding mortality	Fatigue, nausea and vomiting,
Impaired sexual functioning	Diarrhoea, cachexia ( <a href="#">Sapkota et al., 2016</a> )

**Table 5: Opportunities: Resources must be made available to address the concerns of breast cancer survivors during the Covid-19 pandemic**

Breast cancer support group at the district hospital	District level cancer survivor registry
Appointment of coordinators at each Primary health centre.	Inclusion Primary health centre for survivorship care
Telephone/Mobile helpline	For addressing problems of cancer survivors
Telemedicine options	For consultations and referral
Development of community-based cancer survivorship model	For up-gradation current and future cancer survivorship care
Remote monitoring of patient-reported outcomes	self-help strategies and cost-effective health care
Use of Information and Communication Technology	Breast Cancer survivor-centric digital health policy

tative work to overcome stigma, barriers to knowledge and access, and pathways for care is very much scarce compared with the need for it, despite efforts by central and state government, non-governmental organisations working in these areas ([Sullivan et al., 2014](#)).

More emphasis must be given to evidence-based public health policy and health surveillance. The well-planned health policies play a pivotal role in impressive health outcomes. In India, special efforts are required for better health outcomes ([Golechha, 2015](#)). The strategic focus is required on breast can-

cer survivorship; this will reduce barriers related to access to quality multidisciplinary health care.

In this current scenario, there is limited knowledge regarding the Impact of COVID-19 on the outcomes of breast cancer survivors. At this critical time entire population experiencing the feelings so familiar to cancer survivors fears for the future and lack of control ([Koczwara, 2020](#)).

Let's jointly organise community-based breast cancer survivorship model to address challenges of survivorship care to ensure that no breast cancer survivor is ever lost in transition.

## CONCLUSION

The outbreak of the COVID-19 pandemic has now presented breast cancer survivors with new challenges, but also new opportunities to improve their survivorship care. Unique strategies are required to fight with this pandemic. This crisis has also opened doors for some opportunities, and strategic focus must be on the opportunities for future policy-making and implementation. By doing this, we may see success to minimise treatment interruptions and non-adherence. This will help cancer survivors to tackle the adverse situation during and after the COVID-19 era. Breast cancer survivors faced challenges even during the pre-covid19 era. We are currently facing the worst crisis post-independence that has affected all aspects of the Indian community. We have made a list of resources that can be shared with clinicians, breast cancer support group staff and survivors. The breast cancer survivorship health care team, government agencies, support groups, non-government organisations must continue to collect and share evidence and resources that may be of benefit for this vulnerable population.

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## Conflict of Interest

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

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