

# Understanding breast cancer survivorship in Tanzania

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Survivorship in cancer is a relatively new concept in the developing world. Traditionally, the focus of cancer care in this region has been on early identification of cases, provision of curative treatment where possible, and palliative care for the symptoms of advanced disease. However, with an increasing number of patients who are now “survivors”, living with and having completed cancer treatment, there is a growing need to understand and address the unique challenges faced by this group.

According to the National Cancer Institute’s Office of Cancer Survivorship, an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life (1). There are a growing number of individuals living with and after cancer globally – an estimated 43.8 million living within a 5-year diagnosis of cancer as per IARC’s report on Global Cancer Data 2018 (2). Survivorship care requires dealing with a number of different elements in cancer care that may not be typically addressed by standard hospital-based cancer services, including the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases, the ability to get healthcare and follow-up treatment, late effects of treatment, second cancers and quality of life. It also actively involves family members, friends and caregivers (3–5).

## The need for survivorship care in Tanzania

Tanzania is a low-middle income country in East Africa, with a current population of 58.01 million. According to Globocan estimates, 42,080 new cancer cases occurred in 2018, resulting in 26,810 deaths; and over 75,000 prevalent cases existed over a 5-year period in the country. Most cancer cases are treated at the Ocean Road Cancer Institute (ORCI), Tanzania’s national cancer referral centre that provides chemotherapy, radiation therapy, and palliative care, and also serves as a training centre.

Breast cancer (BC) is the second most common cancer among women in Tanzania and accounted for nearly 13% of the 7,650 new cases seen at ORCI in 2018. The majority of patients present with late stage disease, many of them seeking healthcare when they experience pain, skin ulceration or other advanced symptoms (6–8). Typically, patients have undergone surgery (most commonly mastectomy) when they arrive at ORCI for adjuvant therapy; a significant number also present with metastatic disease.

Knowledge about BC varies significantly among women.

Women may be aware about BC but less informed about its symptoms and risk factors; myths surrounding the disease are common and screening for BC is rare (9). Many women are stigmatized and socially isolated after receiving mastectomy. BC in African patients has also been documented in several studies to affect younger women and present in a more aggressive form than that in western countries (10). With only a few centres in the country providing chemotherapy and radiotherapy, patients often have to travel great distances and remain away from their families to access these services. The lengthy treatment involving chemotherapy and radiotherapy for these patients and the impact of distance from family mean that many patients are likely to experience significant physical, emotional and social consequences of the disease and its treatment.

With the increasing number of BC patients living as “survivors” in Tanzania, it was important to understand the needs of this special population and look into ways of providing resources and services where these needs were not being addressed. This article will discuss some of the initiatives instituted at ORCI to address this area.

## The ORCI breast cancer patient support group

This group was established in June 2017 and aimed at providing support to BC survivors and patients currently on treatment at ORCI. The main activity of the group is a monthly meeting currently attended by 40–50 participants. Agendas include self-introductions, health talks given by local or visiting experts (topics range from dealing with side effects of treatment, nutrition, exercise, social support) followed by a question and answer session and a sharing of experiences. The support group often works in collaboration with other local services such as the Tanzania Breast Cancer Foundation and The Aga Khan Hospital. A collaboration with a local volunteer group “Knitters without Borders” has allowed post-mastectomy patients to get free access to crocheted hand-made breast

prostheses (modeled after the “Knitted Knockers” design) through a monthly fitting and distribution scheme supported by the group (11).

The patient support group has become a well-established and popular meeting place for BC survivors, evidenced by the increasing numbers of participants. It is considered a safe and comfortable forum for patients to exchange experiences and provides an excellent opportunity to educate patients, provide peer support and partner with donors and supporters from the community. Facilitating the sharing of experiences and responding to the questions by participants has provided a window of understanding into the informational needs of these patients, which formed the background of a new project to address this gap – the resource centre for patients with metastatic breast cancer.

### The Holistic Needs Assessment (HNA) project

This project, which was funded by the Institute of Cancer Research’s Global Challenges Research Fund (ICR–GCRF), was aimed at exploring the feasibility of implementing the “Recovery Package” (including the holistic needs assessment (HNA), care plan and treatment summary) for patients after primary BC treatment in two African centres (Tanzania and Ghana) (12). The primary objective of the project was to define the unmet needs of women with BC in these centres using the HNA tool and compare this with data from the United Kingdom (already available and published) (13), while the secondary objective was to investigate the real challenges faced by women in these two geographical areas following diagnosis and treatment for BC.

A mixed methods approach was used that included participant observation, focus group discussions with patients, holistic needs assessment and provision of a care plan and/or treatment summary as needed. The Royal Marsden NHS Foundation Trust and the Royal Marsden/Institute of Cancer NIHR Biomedical Research Centre provided support with the research infrastructure. In order to implement this project, the available HNA tool was adapted to meet local cultural needs and translated into the local language. Members of the project team in both centres were trained in conducting HNAs and writing care plans and treatment summaries. Additional training sessions on the principles of qualitative research and mixed methods research, conducting focus group discussions and communication skills were organized. Participants were also trained on gathering and inputting data in a macro-database for statistical analysis.

The results of the participant observation and the focus group discussions with BC survivors highlighted a number of important themes; the lack of resources and facilities, the impact of cultural beliefs and practices in provision and

accessing care, and the important position of the nurse as a navigator in supporting access to cancer services. The role of peer support and sisterhood in resource-challenged environments was also brought to light, as was the importance of the support groups and meetings; the important role media played in the local context of cancer care was also highlighted.

The HNA project generated a dataset of the assessment of needs of 500 women who had undergone surgery for primary BC, and these were analyzed and compared with existing data from the UK dataset. It was realized that there were significant differences in reporting of symptoms and needs between the two African centres, with women in Ghana more likely to report on unmet needs than in Tanzania. There was also a variable use of care plans, and treatment summaries were not deemed important or necessary since a “primary physician model” (for whom the summaries would have been useful) did not exist in these environments, and most women returned to their cancer care centres for their follow-up needs. The results of the HNA project are due to be published soon.

### Nurses training project – The foundations of cancer care

Nurses who participated in the training for the HNA project had expressed an eagerness for focused education in the foundations of cancer care, since many of them had very little specialized training in oncology nursing. A phase 2 project, also funded by the ICR–GCRF was initiated to meet this need. A focused group discussion with the team was held to analyze their learning needs, and a scoping review of literature, e-learning websites and hospice websites was conducted to access currently existing training resources that could be incorporated into the training.

A “Train the Trainer” model was chosen in order to empower participants with adequate resources and skills to allow them to continue training other nurses. The team developed a toolkit (including slides, content and exercises) addressing many of the basic issues in cancer care. Sessions on palliative and end of life care were prepared based on the contents of the World Hospice and Palliative Care Association’s Palliative Care Toolkit (14).

A 5-day teaching schedule was organized with classroom-based teaching in the mornings and patients-based/bedside teaching in the afternoons. Participants were instructed on how to teach and given opportunities at presentations to build their confidence in teaching the content of the course to others. A pre- and post-training confidence assessment was conducted; the evaluation showed a significant increase in the confidence and knowledge of nurses who completed the training in their understanding of basic cancer care and palliative care, and most participants expressed eagerness to continue teaching

this content to other nurses at the institute.

### Resource centre for patients with metastatic breast cancer

ORCI was among the privileged recipients of the SPARC award offered by the Union for International Cancer Control (UICC) jointly with Pfizer Oncology in the year 2019 (15). This award, termed the SPARC (Seeding Progress and Resources for the Cancer Community) is a global grant aimed at supporting new ideas and projects specifically for patients with metastatic breast cancer (MBC). The awarded project plans to establish a resource centre to provide culturally sensitive and relevant information and support to MBC patients. It plans to do this through exploring gaps in the informational needs of women with MBC, developing appropriate patient educational materials, establishing a dedicated office space equipped with necessary tools, training nurses to man the resource centre and establishing a telephone helpline. It is expected that the project will result in development of a culturally acceptable and relevant repository of information accessible to patients with MBC, trained “champions” to disseminate this information, increased awareness about MBC to public and increased recruitment of women to the breast cancer screening clinic.

### Lessons learned

As is the case with other LMICs, Tanzania faces significant challenges in terms of resources and manpower in providing oncology services across the entire spectrum of care, from diagnosis and early detection to palliative care. Establishing and sustaining services for survivors of cancer in these environments can be extremely difficult due to the competing needs of different groups of patients. In such circumstances, collaborations and partnerships with local and international partners can be a lifeline. A significant amount of work has already been done in understanding the needs of this group of patients and establishing services to meet them elsewhere, and much of this can be directly relevant to local settings.

It is however important to continue to work within the context of the individual healthcare set-up, and to recognize the unique cultural differences in needs between populations that may seem similar in other ways – a finding that has been highlighted through the holistic needs assessment project. Integrating survivorship services within existing health systems allows a more equitable use of scant resources, and increases the chances that they will become accepted and sustainable in the long run.

Peer support is crucial, both within patients and within healthcare workers, and should be actively supported. And while the needs of survivors are many, smaller initiatives that are easier to begin and sustain can together have a great impact on the quality of life of these patients. ■

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