

Needs and Opportunities for Information in Patients with Metastatic Breast Cancer Attending a Tertiary Hospital in Tanzania—A Qualitative Study

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How to cite this paper: Dharsee, N., Mwakatobe, K., Haule, M., Tarimo, Q. and Mbwana, M. (2023) Needs and Opportunities for Information in Patients with Metastatic Breast Cancer Attending a Tertiary Hospital in Tanzania—A Qualitative Study. *Advances in Breast Cancer Research*, 12, 63-76.

<https://doi.org/10.4236/abcr.2023.123006>

Received: April 8, 2023

Accepted: June 12, 2023

Published: June 15, 2023

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Abstract

Background: The majority of breast cancer patients in Tanzania present with advanced disease, and a significant proportion has metastatic breast cancer (MBC) on presentation or develops it during the course of their follow-up. With few treatment options to choose from, such patients often benefit from empathic support and access to information to help them make treatment decisions based on their individual circumstances and needs. Patients with MBC have been shown to present with unique physical, social and psychological needs that require additional time, counselling and availability of health care providers in addition to the routine options available to other patients. In resource-limited settings, the needs of such patients are often unknown and unaddressed, which adds to the anxiety associated with the diagnosis and its treatment. **Materials and methods:** This descriptive qualitative study was conducted using 3 focus group discussions with a total of 17 participants with metastatic breast cancer (MBC) attending Ocean Road Cancer Institute in Dar es Salaam, Tanzania. Participants were purposively selected for the study from outpatient clinics and inpatient wards. A semi-structured FGD guide was used to moderate discussions and analysis was done using a thematic approach. **Results:** The median age of participants was 51 (range 33 - 81 years) with an average of 4 months (range 1 - 12 months) from diagnosis of BC to the interview. 4 (24%) were diagnosed with MBC on first presentation (denovo). Participants spoke about the importance of accurate BC-related information in allowing timely referral and treatment both in the community and within the health system. They recognized the role of mass and social

media in increasing awareness about BC and identified myths surrounding cancer treatment especially mastectomy. Correct and timely information at points of care, through media platforms and via ambassadors/patient support groups was perceived as a means to avoiding delays and securing early and effective treatment. **Conclusion:** Patients with MBC in Tanzania have many unmet informational needs in relation to their disease. Accurate BC-related information is important in allowing early detection and diagnosis. At the community level, provision of information through established media platforms and the use of patient advocates may help to enable early referral and treatment of patients.

Keywords

Metastatic Breast Cancer, Information, Needs, Qualitative

1. Background

Breast cancer (BC) is the second most common cancer in women in Tanzania, and the number of new cases of BC diagnosed is expected to increase by 82% by the year 2030 [1]. According to Globocan estimates, breast cancer accounted for 9.9% of cancer cases and 7.3% of cancer deaths in 2020 [2]. A large proportion of women present with advanced (stage 3 and 4) disease, with a significant number having metastatic breast cancer (MBC) on presentation (Denovo MBC) or developing metastatic disease during the course of treatment and follow-up. A meta-analysis of studies done in Sub-Saharan Africa shows that between 4% to 70% of patients present with metastatic disease at first presentation. A single center study done in north-western Tanzania in 2012 showed that 21.4% of women presented with metastatic disease at first presentation [3] [4] [5].

Patients with MBC have been shown to present with unique physical, social and psychological needs that require additional time, counselling and availability of health care providers in addition to the routine options available to other patients [6]. In resource-limited settings, the needs of such patients are often unknown and unaddressed, which adds to the anxiety associated with the diagnosis and its treatment.

Lack of access to timely and accurate information can have significant impact on BC patients' ability to choose and avail of treatment options. A study conducted among women in Nigeria found that, "ignorance of the nature of illness, belief in spiritual healing, fear of mastectomy and belief in herbal treatment were the leading reasons for delay in presentation by women diagnosed with BC" [7]. Despite the large number of patients with MBC in Tanzania, we know very little about their experiences in accessing BC-related information to support them through their cancer journey.

Here, we present the experiences and information needs of patients with MBC attending a tertiary care centre in Tanzania.

2. Materials and Methods

2.1. Study Design

This paper reports on a subset of themes from a qualitative study aimed at understanding the experiences and information needs of patients with MBC attending ORCI. The broader aim of the qualitative study (described below) was to explore participants' experiences during their cancer journey, focusing on access to medical care and BC-related information. Here, we focus on participants' experiences of accessing and obtaining information relevant to their cancer diagnosis including the barriers and facilitators to obtaining information that impacted choices and access to treatment for BC.

This descriptive qualitative study was conducted using 3 focus group discussions (FGDs) with a total of 17 participants with metastatic breast cancer (MBC) attending Ocean Road Cancer Institute in Dar es Salaam, Tanzania. Participants were purposively selected for the study from outpatient clinics and inpatient wards and invited to participate in the study. Inclusion criteria were having a diagnosis of metastatic breast cancer, while patients who refused participation or were unable to communicate due to advanced illness were excluded. Consecutive FGDs were held at intervals of 2 - 4 weeks to accommodate patients who were attending for follow-up clinics. A semi-structured FGD guide was used to moderate discussions and analysis was done using a thematic approach.

2.2. Study Setting

The study was conducted at Ocean Road Cancer Institute (ORCI) which is a national cancer referral centre in Dar es Salaam, Tanzania. ORCI receives cancer patients from all over the country and from around the East and Central African region. The Institute offers a full range of cancer services that include cancer screening, chemotherapy, radiation therapy and palliative care. Patients diagnosed with breast cancer are usually referred to ORCI for adjuvant chemotherapy, hormonal therapy and radiation therapy after surgery. Patients with advanced and metastatic breast cancer are supported by the palliative care team in symptom management and counselling.

2.3. Participants

Participants in this study were women diagnosed with metastatic breast cancer (MBC) attending ORCI for treatment during the study period. Potential participants were recruited from inpatient wards and outpatient clinics and included patients who had MBC at initial presentation as well as those who developed metastatic disease during treatment or follow up.

2.4. Data Collection and Tools

Three FGDs were conducted between April and May 2021 and used a semi-structured FGD guide to moderate discussions, which was developed based on a

literature review as well as the clinical experience of researchers working with patients with MBC. The guide was reviewed several times, and the final version included questions that explored participants cancer journeys, their experiences in receiving care, and their needs and access to information for their condition. Probe questions were added based on participants' responses.

Discussions were held in a comfortable and private seminar room located in the main building of the Institute. Discussions were conducted by KM who has a background in social sciences and extensive experience in qualitative methods of data collection and supported by ND who is also trained in qualitative methods. Before each FGD participants were welcomed, briefed on the proceedings, requested for written informed consent, and assigned numbers which were used to address them during the interview to maintain confidentiality.

FGDs lasted for between one and a half to two and a half hours, and were conducted in Swahili which is the national language and the most common medium of communication at the Institute. Saturation was reached by the third FGD, which means there was repetition of information gained from earlier discussions. FGDs were audio-recorded and notes were also taken to capture additional non-verbal data.

2.5. Data Analysis

Audio-recorded discussions in Swahili were transcribed verbatim immediately after the interview, and the transcripts translated to English. Translations were checked by the first and second author to confirm accuracy and were read and re-read by both authors to familiarize themselves with the data. Data was analyzed using the thematic approach as described by Braun and Clark [8]. The analysis followed six steps of thematic analysis through which initial ideas were generated by two authors, coded and organized into themes. The final report is presented with codes and themes together with supporting quotes [9] [10].

2.6. Ethics Approval and Consent to Participate

Ethical approval to conduct this study was obtained from the Institute Academics, Research, Publications, and Ethical Committee of Ocean Road Cancer Institute through approval number 10/VOL.XX/66B. Participants provided written informed consent for interviews and recording.

3. Results

3.1. Participant Characteristics

A total of seventeen (17) women participated in the three FGDs. The median age was 51 (range 33 - 81) years. There was an average of 4 months (range 1 - 12 months) duration from diagnosis of BC to the interview. 4 (24%) women were diagnosed with MBC on first presentation (*denovo*), the rest developed it during the course of their journey with BC.

3.2. Themes

Three major themes emerged from the discussions, with six supporting sub-themes. These are presented together with associated codes in **Table 1**.

Theme 1: Patients' needs for BC-related information.

This theme illustrates the experiences and needs of BC-related information among patients.

Sub-theme 1: Impact of correct and incorrect information on BC.

Participants spoke about the negative impact that false or inaccurate information regarding cancer had on their experience. Many described their reluctance to seek medical care because the swelling they discovered in the breast was painless, while others spoke about how family members discouraged them from seeking treatment, resulting in their seeking alternative methods and delaying their medical care.

At first, my breast started to swell but I didn't feel any pain. So, I ignored it thinking that it was normal (FGD3, Respondent 2).

I started feeling a small tumor on my breast in 2018. It was increasing every month. I didn't feel any pain. I live with that condition until 2019. The breast was still swelling. In June 2019 I decided to go to hospital. (FGD3, Respondent 3)

Some of my relatives advised me to consult religious people and ask for prayers. They thought maybe I was bewitched. (FGD 1, Respondent 8)

Table 1. Themes, sub-themes and codes.

Themes	Sub-themes	Codes
1 Patients' needs for BC-related information	Impact of correct and incorrect information about BC	Belief that cancer is incurable prevents seeking treatment
		Correct information allows early treatment of BC
	Need for accurate BC-related information	Self-diagnosis and early referral due to prior information on BC
		Myths about mastectomy as a form of treatment
Potential sources of information	Need for knowledge on risk factors and how to prevent BC	
	Need for understanding on advanced BC and its implications	
2 BC awareness in the health system	Need for BC awareness among health care workers	The role of health facilities in creating awareness
		Information can be shared in the community through printed material, mass and social media
		HCWs lack expertise to diagnose BC
3 Potential role of patients in creating awareness	Patients can serve as a support system	Delayed treatment due to misdiagnosis
		Need for Improved communication between hospitals
	Patients as ambassadors in the community	Patients sharing information and supporting each other while on treatment
		Survivors inspire and empower patients to complete treatment
		Survivors should educate women in the community
		Patients can distribute available material to create awareness

Thereafter, my breast started swelling. It started slowly and grew into a big abscess. I informed my relatives, but they ignored me. They said I should just wait and relax. So, I just stayed at home. (FGD2, Respondent 3)

Several participants narrated how the delay to accepting surgery as a treatment option was affected by myths and wrong information about the mastectomy. Concerns that removing the breast would affect fertility or result in death was a common reason cited by relatives who discouraged surgery.

They (family) disagreed with the advice to remove my breast. They asked me why I wanted to get my breast removed and whether I was still able or wanted to have children! They completely did not want me to remove the affected breast. So, I just stayed. (FGD1, Respondent 2)

Some people even tried to scare me, telling me that once I have breast removal surgery I will die right away. (FGD1, Respondent 1)

On the other hand, there were also positive experiences among patients who had received information about BC from the radio or other sources. Some participants were able to self-diagnose a breast lump and seek medical care while others described how they conducted breast self-examination regularly, through which they were able to detect the lumps.

One day I was taking my shower and I touched my breast on this side, where I found a small tumor. I asked myself how come I had that tumor! With all the information I had heard, I told myself it could be cancer. (FGD2, Respondent 4)

I used to listen to the radio and assess my breasts almost every day. I was really careful. (FGD2, Respondent 1)

I already had prior information about it. There were campaigns about breast cancer. So, when I performed self-screening and found that abnormal breast tissue on me—a tumor—I knew it was cancer. I knew that I just needed to go to the hospital to seek treatment. I didn't worry. So, I calmed down. (FGD2, Respondent 4)

Sub-theme 2: Need for accurate BC-related information.

Participants expressed the need for accurate information on BC which would help their understanding of the condition. Specifically, they wanted to know regarding the causes and risk factors of BC and how to prevent it from occurring.

We are just told that this is breast cancer, but what are its causes? (FGD2, Respondent 4)

I would like to know more about it. In the past they used to say cancer is passed down genetically through heritage, but I think there is nothing like that anymore. We have never had it in our family. (FGD2, Respondent 1)

What kinds of food do I need to eat to prevent cancer? (FGD2, Respondent 1)

In describing their understanding of advanced cancer and its implications, participants generally understood that advanced cancer was a worse stage in cancer, was incurable, or meant that they would die soon. However, among other participants there was confusion or clear misunderstanding of the concept of cancer stage.

The way I understand it...if someone tells you have an advanced stage cancer, it means it has gone beyond. It means you can't be cured. (FGD2, Respondent 4)

You become so worried. You will just need to accept the news. I will simply tell myself that now I'm nearing my end. I will thank God, and nothing else. (FGD3, Respondent 4)

...but I don't know the stage my cancer has reached. I hear other people talking about stages of cancer: others are in stage 4, others 3, others 2, and others at stage 1. So, I don't know where I belong, whether stage 4, 3, 2, or 1. (FGD1, Respondent 8)

One participant believed “advanced stage” meant an improvement in her diagnosis, although she admitted she wasn't very sure about it.

I was thinking that when you are told that your cancer has reached an advanced stage it means you are improving. In my opinion, I think it refers to my improvement after receiving treatment. That is why the expert says you have reached an advanced stage. That is according to my understanding. I'm not sure if I'm right or not. (FGD3, Respondent 1)

Sub-theme 3: Potential sources of information.

Most participants spoke about the role of mass media in creating awareness and disseminating information about BC. The television, SMS messages via phones were among the frequently cited sources. Others talked about printed media in the form of brochures and books as important sources.

I think it is through media because media carries everything. I just propose the media. You could send information to TBC for it to broadcast so that everyone can understand. (FGD1, Respondent 5)

I also think that mass media can be used. In addition, we can also use telephone to what to do and where to access the services. (FGD1, Respondent 6)

I think maybe through written and printed materials... (FGD2, Respondent 5)

You could broadcast some programs on radio... (FGD3, Respondent 1)

One participant described how information learnt over the radio helped her practice breast self-examination.

I had access to the information through the radio. Because I use the minibus to and from work every day, and they switch on the radio. Once I heard that information, I developed the behavior of examining my own breasts every morning. (FGD 2, Respondent 1)

Participants also recognized that health facilities have an important role in creating awareness about BC, either directly from the facility itself, or through participating in mass media campaigns.

A doctor or a health expert could be invited to a radio station to talk about the disease... They also need to insist on seeking early treatment to optimize the chances of getting cured. (FGD3, Respondent 1)

But we also need to consider other channels. Such as the hospitals themselves. When we disseminate the information through hospitals, everyone going to the hospital will be able to access the message and understand where to seek assis-

tance. (FGD1, Respondent 2)

Fliers, Give them to healthcare facilities and people will get them from there. (FGD3, Respondent 3)

Theme 2: BC awareness in the health system

This theme describes challenges and opportunities at the health system level in creating awareness about BC. It has one main sub-theme.

Sub-theme 4: Need for BC awareness among health care workers

Many participants expressed concern about the lack of expertise in diagnosing and managing suspicious breast lumps among health care workers in lower-level facilities. They expressed how a lack of equipment, knowledge and information contributed to misdiagnosis, sometimes due to a belief of other (e.g. hormonal) causes of the symptoms, and sometimes due to a lack of expertise (e.g. pathology, surgery) to diagnose the lump, which led to unnecessary delays in referral and treatment.

Having noticed that, I decided to go see the doctors for advice. But when they asses my situation they always said I didn't have a big problem. They said it was just hormonal imbalance that caused the tumor. So, they allayed all the fear from me that it was nothing to worry about, just hormonal imbalance. That made me to wait for a long time before seeking proper treatment. (FGD2, Respondent 5)

I was admitted but they could not diagnose the problem... So, they told me they were not able to diagnose the problem. (FGD1, Respondent 4)

Had my cancer been diagnosed early enough and initiated into treatment right away, I would have been home now fully recovered. But I was diagnosed late. a health expert should help you move to a better treatment option until you find a solution to your problem. That would have helped a lot. (FGD1, Respondent 1)

Participants also spoke about the need for improved communication between hospitals to smoothen the referral process and care. They expressed how workers in general facilities avoid accepting cancer patients who are under treatment. They described how a lack of complete documentation and communication between referring and receiving facilities poses unnecessary stress and burden to the patients.

Usually, they are afraid of treating us. I think this is because we don't have close relationships with the local healthcare facilities in the areas where we come from. (FGD2, Respondent 5)

I think that things should be handled differently: there needs to be improved two facilities as far as logistics are concerned. (FGD1, Respondent 1)

Theme 3: Potential role of patients in creating awareness.

The third theme covers participants views about the role patients can play in creating awareness about breast cancer in the community.

Sub-theme 5: Patients can serve as a support system.

Participants spoke about how BC patients can provide support to other patients by providing relevant information in their cancer journey. Social media

such as WhatsApp groups was mentioned as a potential platform to connect and communicate.

As we know, the world has become a small village. We can create a WhatsApp group for those of us who have been treated at this hospital. So, in case one of us finds any hints about cancer, they can post it that there. (FGD3, Respondent 1)

So, you can also use us as your ambassadors to send messages to others. Once we leave this place, we can meet two or three other women and we will share information with them. That is how we disseminate information. (FGD1, Respondent 8)

Sub-theme 6: Patients as ambassadors in the community.

Participants also recognized their roles as potential advocates for cancer in the community. They spoke of how they could share printed information, visit neighbours and family to raise awareness about BC. They asked to be given copies of printed material to take back to their villages for distribution.

...whoever gets cured, whoever feels better, thanks God, needs to educate others in her community using the books or other materials... whoever visits me at my house, I will show her the book for her to read and understand. (FGD3, Respondent 1)

When I'm on my way home, before boarding the ferry, I could wait for 30 minutes during which time I can distribute the flyers to my fellow passengers or those who just arrived from. People will read and understand the message... (FGD3, Respondent 1)

But for us who have had cancer, we need to get copies of the book because we are here. You can just give us copies of it for us to read and educate other members of our households. With education, we can be able to notice if someone is showing symptoms of cancer or else and be able to help take the person to the hospital. (FGD3, Respondent 1)

4. Discussion

Trustworthiness of the study

For qualitative studies, trustworthiness is assessed by using four criteria; credibility, transferability, confirmability and dependability [9]. We ensured credibility by including participants with MBC from different backgrounds, and data collection by authors who have vast experience in interacting with patients with BC. To enhance transferability, a thick description of the study context is provided so that findings can be transferred to a site with a similar context. Authors with different educational and professional backgrounds participated in the study process to enhance confirmability. All presented themes and sub-themes are supported by codes and quotes. Dependability was enhanced through good documentation of the research process that can be traced.

Themes

This paper focuses on the themes that were generated in relation to informational needs of women with metastatic breast cancer. We found that patients had

many unmet informational needs particularly in relation to diagnosis, treatment, and risk factors of BC, which is in keeping with studies done elsewhere. Davinia *et al.*, in an assessment of patients with MBC in their first year after diagnosis found that most participants had high informational needs, and were most interested in information about treatment and disease [11]. In a systematic review of studies on health information seeking behaviour of breast cancer patients, Ravangard found a high level of unmet informational needs, and also a high degree of dissatisfaction with information provided by care providers [12]. Other studies have repeatedly demonstrated the needs for information among BC patients across their cancer journey and even as survivors [13] [14] [15], and others have shown association between having informational needs met and satisfaction with care [16].

A major impact of having access to information in our settings is to help patients make decisions about treatment and seek early medical intervention. We found that the availability of accurate BC-related information was very important to our participants, and a lack of correct information was believed to contribute to delays in seeking treatment. This is often because there is generally a low level of knowledge about cancer in the community. A study conducted in Mwanza, Tanzania by Chao *et al.* found similar experiences among women in their perspectives for BC control. On a scale from 1 to 10, women self-rated their knowledge of BC to be very low (Median 3; IQR 1 - 4). Only 13.7% said they knew breast cancer symptoms, and 23.6% reported self-examining their breasts. Fear of losing a breast was the most commonly listed barrier to seeking care [17].

One of the themes emerging from this study was the contribution of the health system to delays in treatment. Participants highlighted the need for BC awareness among health workers, describing how lack of knowledge and expertise could lead to delays in providing treatment. This is a commonly encountered situation in LMICS, as described by Jedy-Agba *et al.* In this comprehensive systematic review of studies describing stage at diagnosis in BC patients in sub-Saharan Africa, the authors confirm that most patients were diagnosed at a late (stage III/IV) stage. Among the factors discussed that contribute to delays are poor knowledge among health workers, (through misdiagnosis, with false reassurance of patients and sometimes inappropriate treatment, such as antibiotics for presumed mastitis). In addition, dysfunctional referral pathways in fragmented health systems contribute to patients presenting at oncology centres with advanced cancers [3] [18].

Myths associated with BC treatment and fear of mastectomy featured importantly in our study, and has been documented by other authors [7]. For African women, accepting the surgical removal of a breast is still a difficult choice to make. Odigie *et al.* who looked at psychosocial effects of mastectomy among Nigerian women, showed that 67.9% of their study population felt inadequate as a woman because of the mastectomy, and 38.3% were divorced or separated from their husbands 3 years after primary breast care treatment [19].

Many participants in our study recommended the use of mass media for disseminating information about BC. They also noted the role of the health care system for this purpose. Other authors have reported similar findings [20]. A study among women with BC in Lebanon found that the doctor was the major source of information for patients followed by media (radio and television) [13]. This increased community knowledge and awareness is expected to contribute towards reducing the stigma of the diagnosis and increasing earlier presentation by improving the health seeking behaviour of communities [21].

As part of the solutions facing challenges with informational needs, participants in our study showed enthusiasm to serve as patient advocates and ambassadors in the community. They felt motivated to create awareness in the community about the presentation of BC and to serve as witnesses for having survived its treatment. While this may be relatively underdeveloped in our setting, the role of patients as ambassadors and advocates is now well established in western countries, and there exist a number of platforms to support this cause. Websites of a variety of institutions dealing with cancer provide information and link patients with support groups [22] [23]. Moreover, there are opportunities to train and empower patients to take on these roles in which they can be effective ambassadors for change in the community and within the health systems, such as the National Breast Cancer Coalition (NBCC) Advocacy Training, and the Union for International Cancer Control (UICC) Cancer Advocates Program [24] [25].

Patients themselves can benefit from taking on advocacy roles by obtaining a sense of purpose and feeling empowered to make a difference in other patients cancer journeys as documented by a young patient with MBC [26]. As documented by Ganz, “At any step along the diagnostic and treatment continuum (Figure), there are important points where patients can benefit from active advocacy. The past experience and knowledge of physicians, nurses, and social workers position them to take on this role” [27]. A qualitative study by Dvadze *et al.* on BC advocacy in Low and Middle Income Countries concluded that “Cancer survivors and advocates are valuable sources of information and powerful resources for advancing cancer control, yet a lack of trust, knowledge gaps, stigma, and limited organizational capacity and resources hamper their efforts to improve cancer care and outcomes in their communities. When supported and provided with accurate information and opportunities to network, advocates are better equipped to pursue evidence-based programs, advocate for appropriate solutions, and hold their governments accountable to the commitments”.

5. Study Limitations

Our study was conducted with a small sample in one cancer centre in Tanzania; hence the results of this study may have limited generalizability. However, we note that our participants came from different regions across Tanzania, and

their situation and circumstances are like those of many settings in LMICS, and particularly in Africa; therefore, these findings may be transferrable to other similar settings.

6. Conclusion

Patients with MBC in Tanzania have many unmet informational needs in relation to their disease. Accurate BC-related information is important in allowing early detection and diagnosis, and there is room for education and sensitization to cancer diagnoses in the health system. At the community level, provision of information through established media platforms and the use of patient advocates to provide support and increase awareness may help to improve acceptability of diagnoses and secure social support, enabling early referral and treatment of patients.

Acknowledgements

This work has been supported by a UICC SPARC MBC Challenge Grant.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

References

- [1] Breast Cancer Initiative 2.5 (BCI2.5) on Behalf Ministry of Health Community Development Gender Elderly and Children of the United Republic of Tanzania (2017) Tanzania Breast Health Care Assessment 2017. An Assessment of Breast Cancer Early Detection, Diagnosis and Treatment in Tanzania. https://ww5.komen.org/uploadedFiles/_Komen/Content/What_We_Do/Around_the_World/Africa/Tanzania-BHCA-2017.pdf
- [2] (2020) Global Cancer Observatory: Cancer Today. Tanzania, United Republic. International Agency for Research on Cancer. <https://gco.iarc.fr/today/data/factsheets/populations/834-tanzania-united-republic-of-fact-sheets.pdf>
- [3] Jedy-Agba, E., McCormack, V., Adebamowo, C. and Dos-Santos-Silva, I. (2016) Stage at Diagnosis of Breast Cancer in Sub-Saharan Africa: A Systematic Review and Meta-Analysis. *The Lancet Global Health*, **4**, e923-e935. <https://pubmed.ncbi.nlm.nih.gov/27855871> [https://doi.org/10.1016/S2214-109X\(16\)30259-5](https://doi.org/10.1016/S2214-109X(16)30259-5)
- [4] Nabawanuka, A., Galukande, M., Nalwoga, H. and Gakwaya, A. (2013) Metastatic Breast Cancer and Hormonal Receptor Status among a Group of Women in Sub Saharan Africa. *The Annals of African Surgery*, **10**, 7-11. <https://doi.org/10.4314/ahs.v12i4.4>
- [5] Mabula, J.B., Mchembe, M.D., Chalya, P.L. and Giiti, G. (2012) Stage at Diagnosis, Clinicopathological and Treatment Patterns of Breast Cancer at Bugando Medical Centre in North-Western Tanzania. *Tanzania Journal of Health Research*, **14**, 269-279. <https://doi.org/10.4314/thrb.v14i4.6>
- [6] Tucker, C.A., Pilar Martin, M. and Jones, R.B. (2017) Health Information Needs,

- Source Preferences and Engagement Behaviours of Women with Metastatic Breast Cancer across the Care Continuum: Protocol for a Scoping Review. *BMJ Open*, **7**, e013619. <https://doi.org/10.1136/bmjopen-2016-013619>
- [7] Ibrahim, N.A. and Oludara, M.A. (2012) Socio-Demographic Factors and Reasons Associated with Delay in Breast Cancer Presentation: A Study in Nigerian Women. *The Breast*, **21**, 416-418. <https://doi.org/10.1016/j.breast.2012.02.006>
- [8] Braun, V. and Clarke, V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, **3**, 77-101. <https://doi.org/10.1191/1478088706qp0630a>
- [9] Nowell, L.S., Norris, J.M., White, D.E. and Moules, N.J. (2017) Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, **16**, 1-13. <https://doi.org/10.1177/1609406917733847>
- [10] Kiger, M.E. and Varpio, L. (2020) Thematic Analysis of Qualitative Data: AMEE Guide No. 131. *Medical Teacher*, **42**, 846-854. <https://doi.org/10.1080/0142159X.2020.1755030>
- [11] Seah, D.S.E., Lin, N.U., Curley, C., Winer, E.P. and Partridge, A.H. (2014) Informational Needs and the Quality of Life of Patients in Their First Year after Metastatic Breast Cancer Diagnosis. *Journal of Community and Supportive Oncology*, **12**, 347-354. <https://doi.org/10.12788/jcso.0077>
- [12] Ravangard, R., *et al.* (2020) Health Information Seeking Behavior of Breast Cancer Patients: A Qualitative Study.
- [13] Nader, E.A., Kourie, H.R., Ghosn, M., El Karak, F., Kattan, J., Chahine, G., *et al.* (2016) Informational Needs of Women with Breast Cancer Treated with Chemotherapy. *Asian Pacific Journal of Cancer Prevention*, **17**, 1797-1800. <https://doi.org/10.7314/APJCP.2016.17.4.1797>
- [14] Shea-Budgell, M.A., Kostaras, X., Myhill, K.P. and Hagen, N.A. (2014) Information Needs and Sources of Information for Patients during Cancer Follow-Up. *Current Oncology*, **21**, 165-173. <https://doi.org/10.3747/co.21.1932>
- [15] Mistry, A., Wilson, S., Priestman, T., Damery, S. and Haque, M. (2010) How Do the Information Needs of Cancer Patients Differ at Different Stages of the Cancer Journey? A Cross-Sectional Survey. *JRSM Short Reports*, **1**, Article No. 30. <https://doi.org/10.1258/shorts.2010.010032>
- [16] Tran, Y., Lamprell, K., Nic Giolla Easpaig, B., Arnolda, G. and Braithwaite, J. (2019) What Information Do Patients Want across Their Cancer Journeys? A Network Analysis of Cancer Patients' Information Needs. *Cancer Medicine*, **8**, 155-164. <https://doi.org/10.1002/cam4.1915>
- [17] Chao, C.A., Huang, L., Visvanathan, K., Mwakatobe, K., Masalu, N. and Rositch, A.F. (2020) Understanding Women's Perspectives on Breast Cancer Is Essential for Cancer Control: Knowledge, Risk Awareness, and Care-Seeking in Mwanza, Tanzania. *BMC Public Health*, **20**, Article No. 930. <https://doi.org/10.1186/s12889-020-09010-y>
- [18] Cumber, S.N., Nchanji, K.N. and Tsoka-Gwegweni, J.M. (2017) Breast Cancer among Women in Sub-Saharan Africa: Prevalence and a Situational Analysis. *Southern African Journal of Gynaecological Oncology*, **9**, 35-37. <https://doi.org/10.1080/20742835.2017.1391467>
- [19] Odigie, V.I., Tanaka, R., Yusufu, L.M.D., Gomna, A., Odigie, E.C., Dawotola, D.A., *et al.* (2010) Psychosocial Effects of Mastectomy on Married African Women in Northwestern Nigeria. *Psycho-Oncology*, **19**, 893-897. <https://doi.org/10.1002/pon.1675>
- [20] Kowalski, C., Lee, S.D., Ansmann, L., Wesselmann, S. and Pfaff, H. (2014) Meeting

- Patients' Health Information Needs in Breast Cancer Center Hospitals—A Multilevel Analysis. *BMC Health Services Research*, **14**, Article No. 601. <https://doi.org/10.1186/s12913-014-0601-6>
- [21] Mutebi, M. and Edge, J. (2014) Stigma, Survivorship and Solutions: Addressing the Challenges of Living with Breast Cancer in Low-Resource Areas. *South African Medical Journal*, **104**, Article No. 383. <https://doi.org/10.1111/j.1547-5069.1990.tb00225.x>
- [22] Breast Cancer Patient Support Group. https://www.cancercare.org/support_groups/43-breast_cancer_patient_support_group
- [23] The Importance of Breast Cancer Advocacy: Insights from the Community. Bristol Myers Squibb. <https://www.bms.com/life-and-science/science/importance-of-breast-cancer-advocacy-and-community-insights.html>
- [24] Advocacy. National Breast Cancer Coalition. <https://www.stopbreastcancer.org/focus/advocacy/>
- [25] UICC Cancer Advocates Program. <https://www.uicc.org/what-we-do/member-benefits/learning-and-development/cancer-advocates-programme>
- [26] Patient Finds Purpose Advocating for Others with Metastatic Breast Cancer. <https://cancer.osu.edu/blog/patient-finds-purpose-advocating-for-others-with-metastatic-breast-cancer>
- [27] Ganz, P.A. (1995) Advocating for the Woman with Breast Cancer. *CA: A Cancer Journal for Clinicians*, **45**, 114-126. <https://doi.org/10.3322/canjclin.45.2.114>