

Exploring Stigma as a Barrier to Cancer Service Engagement: Illness Narratives of Breast  
Cancer Survivors in Kampala, Uganda

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**Abstract**

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*Aim:* The purpose of this study is to understand the role of stigma in delaying cancer service engagement for women with breast cancer in Kampala, Uganda.

*Background:* Women in African countries are twice as likely to die from cancer than women in high-income countries.<sup>1</sup> While access to care is limited, the high case fatality is largely attributable to late diagnosis of cases, 75-90% of women in sub-Saharan Africa are diagnosed in stage 3 and 4, significantly reducing survival.<sup>3</sup> Stigma associated with breast cancer has been identified by previous studies in sub-Saharan Africa, however there is limited research focused on how this stigma impacts the behavior of breast cancer patients in Uganda.

*Method:* This qualitative study uses a grounded theory approach to examine 20 illness narratives of breast cancer survivors in Uganda, gathered through in-depth semi-structured interviews. All data were collected between November-December 2014.

*Findings:* Analysis of the data uncovered how social stigma and self-stigma associated with breast cancer impact care engagement throughout the illness experience for survivors in Uganda. The thematic analysis results showed how stigma not only delays women from engaging in care early, but also discourages women from remaining engaged with care through to treatment completion. Key factors to overcoming the stigma and engaging in care included acceptance of diagnosis, strong social support and knowledge of breast cancer.

*Conclusion:* The growing burden of mortality associated with breast cancer worldwide can be stemmed by improving early detection through evidence-based interventions, which include accounting for key psychosocial barriers, such as stigma.

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## **LIST OF ACRONYMS & ABBREVIATIONS**

BSE	Breast Self Exam
IARC	International Agency for Research on Cancer
NCI	National Cancer Institute
UCI	Uganda Cancer Institute
UWOCASO	Uganda Women's Cancer Support Organization

## **ACKNOWLEDGMENTS**

The success of this study is due to the support of all our partners: the Uganda Cancer Institute, the Uganda Women's Cancer Support Organization and the University of Washington. I would like to express my sincere appreciation to Dr. Deepa Rao, who developed this study and invited me to join. I am grateful for her guidance and support through this entire process. I am indebted to all of the breast cancer survivors in Uganda who were willing to share their illness experiences and are committed to improving care for patients. This research was made possible with generous funding from the National Cancer Institute. Thank you for believing in this research.

## INTRODUCTION

### Background

In sub-Saharan Africa, breast cancer is a leading cause of cancer related death with the incidence growing every year.<sup>1</sup> Women in African countries are twice as likely to die from cancer than women in high-income countries.<sup>1</sup> In 2012, the African Cancer Registry Network and International Agency for Research on Cancer (IARC) estimated Uganda had an age-standardized incidence rate of 27.5 per 100,000 women, one of the highest in the region.<sup>2</sup> While access to care is limited, the high case fatality is largely attributable to late diagnosis of cases, 75-90% of women in sub-Saharan Africa are diagnosed in stage 3 and 4, significantly reducing survival.<sup>3</sup> Additionally, breast cancer patients are often unwilling to engage in treatment recommendations even after diagnosis, further delaying care and contributing to poor outcomes.<sup>3,4</sup> Several studies have focused on determining the barriers to engagement with cancer services, which have included factors at economic, healthcare, geographic and sociocultural levels.<sup>3</sup>

In Uganda, a qualitative study with breast cancer survivors identified fear as primary barrier to seeking early detection.<sup>1</sup> This included fear of death after diagnosis, fear of biopsy or surgery and fear of losing familial and social support.<sup>1</sup> Breast cancer survivors attribute familial support as contributing to early service engagement and detection, without this encouragement they may have delayed.<sup>1</sup> Similarly, in 2011, De Ver Dye et al. conducted a mixed-methods study to assess the beliefs and practices around breast cancer in Ethiopia which found a culture of social stigma driven by the poor prognosis of the disease.<sup>5</sup> The isolation of the stigma, meant women avoided screening or hid their diagnosis, to avoid social exclusion.<sup>5</sup> Their reaction to stigma delayed health service engagement.<sup>5</sup>

In neighboring Kenya, a qualitative study by Muthoni et al., examined the knowledge and attitudes about breast cancer among both urban and rural Kenyan women, highlighting the need for more awareness about the symptoms and severity of breast cancer and the importance of early detection.<sup>4</sup> Kenyan women often waited to seek medical care until they were in excruciating pain or had discharge from their breasts.<sup>4</sup> This was true for both urban and rural women, despite a higher knowledge of breast cancer risk factors among urban women.<sup>4</sup> Both groups of women viewed breast cancer as very severe, but stigma, fear and the high fatalism resulted in fewer rural or lower-income urban women from perceiving a benefit to early detection.<sup>4</sup> For urban women, the primary benefit of early detection was time to organize their affairs and prepare for their family for their death.<sup>4</sup> For both groups of women, fear of losing husbands or family after diagnosis contributed to feelings of shame and stigma.<sup>4</sup>

Stigma is a significant barrier to uptake of screening, diagnostic services, and engagement in care for women with breast cancer, particularly with diverse populations within and outside of the United States. The social and cultural stigma found in studies in both Ethiopia and Uganda resulted in self-stigmatization, which delayed care engagement.<sup>5,6</sup> Internalized stigma or self-stigma, as defined by Corrigan, is when a person who has a stigmatized disease feels the negative social stigma associated with the disease applies to them.<sup>7</sup> Self-stigma has already been proven to contribute to delaying health seeking behaviors with other medical diseases such as HIV.<sup>8,9</sup>

Despite this clear link between stigma and engagement in cancer screening and treatment services, Sharma et al.'s systematic review of the literature on barriers to breast cancer care in developing countries, discovered a lack of research to adequately address the impact on delayed patient presentation.<sup>10</sup> Additionally, Smith et al. emphasize the importance of considering social and cultural barriers to care in order to implement successful early detection programs in

limited-resource countries.<sup>11</sup> To address this gap, our pilot study aims to gather information on how internalized stigma associated with breast cancer impacts cancer service engagement. Additionally, this study aims to obtain feedback on avenues for intervention to inform the development of a stigma reduction intervention for breast cancer in Uganda.

To address our research goals, we aim to interview breast cancer survivors about their illness narratives. This approach has been utilized by other studies<sup>6,12</sup>, especially in settings with a survivor-advocate groups, such as the Uganda Women's Cancer Support Organization (UWOCASO) in Kampala. Research has shown that survivor's personal illness testimonies are an important factor for promoting health behavior change.<sup>4-6,12</sup> This is consistent with health behavior change models, such as The Transtheoretical Model, which notes how personal testimonies can provide an emotional connection to a health behavior, which contributes to a person changing their behavior.<sup>13</sup> This research hopes to tap these personal testimonies of survivors to better understand the barriers stigma place on care-engagement, to guide effective interventions to improve early care-seeking behavior and reduce stigma.

This study comes from the collaboration of University of Washington, the National Cancer Institute's Center for Global Health, Cancer Association, Uganda Women's Cancer Support Organization (UWOCASO) and the Uganda Cancer Institute (UCI).

## **METHODS**

### **Study Design**

This is a qualitative study nested within a larger mixed-methods pilot study exploring intervention tools for reducing stigma around breast cancer in Uganda. Due to the lack of prior

research on stigma and breast cancer in Uganda, the epistemological orientation of the study was exploratory and based in Grounded Theory.

The study was granted Institutional Review Board approval by the University of Washington, Makerere University in Kampala and Uganda's National Council of Science and Technology. All study activities met the ethical standards set forth by all committees to ensure the protection of study participants. All participants received an informed consent information sheet, which was explained to them and then participants provided oral consent. Written consent was waived to ensure participant confidentiality. Interviews were digitally recorded with consent of the participant. All participants were offered a snack and a \$10 USD transportation reimbursement.

### **Sampling**

We sampled 20 breast cancer survivors from Uganda. To be eligible for the study, survivors had to have received their treatment in Uganda or East Africa, have been in remission for at least a year, be at least 18 years old and fluent in English. Current patients or survivors experiencing a recurrence were ineligible to participate due to ethical concerns with questioning them about their health-seeking behaviors. With the assistance of UWOCASO, study participants were recruited by phone or in person.

### **Data Collection**

All data was collected in Kampala between between November-December 2014. Demographic information on all participants was collected, including age, education, parity, breastfeeding history, family history of cancer, marital status, dates of diagnosis, stage of diagnosis and location of treatment.

Qualitative data was collected through in-depth semi-structured interviews about their illness narratives, guided by questions in Appendix A. The interview questions were developed to

guide participants to share their experiences, health-seeking behaviors and feelings from their first symptom through to treatment completion. To target better understanding of stigma and self-stigma, the researcher probed participants with follow-up questions when topics related to an experience of stigma were brought-up; questioning was flexible in relation to each participant's responses. This questionnaire was developed with the assistance of UWOCASO and UW researchers.

Interviews were conducted at the offices of UWOCASO in a private room, to ensure participants felt comfortable discussing sensitive illness narratives. Interviews were conducted in English and lasted between 60-90 minutes. All interviews were digitally recorded following an oral informed consent process with participants. A Ugandan research assistant transcribed the recordings of the interviews, which were used for data analysis.

### **Data Analysis**

The transcribed interviews were imported to Atlas.ti for coding and determining themes from the data. The researcher used a Grounded Theory approach for data analysis.<sup>14</sup> All transcripts were coded line by line using open coding to develop a codebook. The codes were compiled into categories and themes by the researcher. Both within-case and across-case analysis was employed. The within-case analysis focused on the individual illness narratives, the experiences of internal and social stigma and how this impacted their health service engagement. The across-case analysis aimed to examine the differences and similarities between the illness narratives of the breast cancer survivors. Key quotes from the transcriptions are used to demonstrate the results from the analysis.

## RESULTS

Demographic data was collected from 20 breast cancer survivors, all of whom participated in in-depth interviews. The participant age ranged from 35-67 years old. The majority of survivors were diagnosed with breast cancer between the ages of 40-49 years. Most participants were diagnosed in either stage I or II. Participants survivorship ranged from 1 -12 years. All the women who were interviewed had children and most had breastfed. Almost all participants received treatment in Kampala; three participants received a portion of their treatment in Nairobi (See Table 1). All participants were currently or had been members of UWOCASO.

Analysis of the transcribed in-depth interviews illuminated the illness experiences of the breast cancer survivors, highlighting the numerous barriers and facilitators to women engaging and staying with care during their journey with breast cancer. During

symptom discovery, diagnosis, treatment initiation, participants described their behaviors and factors, which led to their decisions to engage in care and continue to complete treatment, which included over-coming stigma.

<b>Table 1: Study Participant Demographics</b>	
<b>Characteristic</b>	<b>Interview Frequency (%)</b>
<b>Total</b>	<b>20 (100.0)</b>
<b>Age of Participant (years)</b>	
30-39	<b>1 (5.0)</b>
40-49	<b>8 (40.0)</b>
50-59	<b>6 (30.0)</b>
60-69	<b>5 (25.0)</b>
<b>Age at Diagnosis (years)</b>	
20-29	<b>2 (10.0)</b>
30-39	<b>4 (20.0)</b>
40-49	<b>11 (55.0)</b>
50-59	<b>3 (15.0)</b>
<b>Stage at Diagnosis*</b>	
I	<b>7 (35.0)</b>
II	<b>8 (40.0)</b>
III	<b>4 (20.0)</b>
IV	<b>0 (0.0)</b>
<b>Marital Status</b>	
Married	<b>11(55.0)</b>
Separated (or divorced)	<b>2 (10.0)</b>
Widowed	<b>4 (20.0)</b>
Single	<b>3 (15.0)</b>
<b>Parity</b>	
1-2	<b>7 (35.0)</b>
3-4	<b>6 (30.0)</b>
5+	<b>7 (35.0)</b>
<b>Education</b>	
Primary	<b>1 (5.0)</b>
Secondary	<b>4 (20.0)</b>
University (+)	<b>15 (75.0)</b>
<b>Family History of Cancer</b>	
Yes	<b>8 (40.0)</b>
<b>Breastfed Children</b>	
Yes	<b>19 (95.0)</b>

\*One missing value

During analysis, a codebook was developed from common topics shared by survivors. The researcher used these 45 codes to compile categories related to stigma experienced by survivors, health seeking behaviors and coping mechanisms as described. Once the data was organized into categories, common themes emerged explaining how these participants overcame breast cancer.

A conceptual model was developed from the common themes discovered from the analysis of the illness narratives (See Figure 1). This conceptual model demonstrates the key success factors at critical periods during the illness experience, which survivors identified as instrumental in overcoming stigma and staying engaged with care.

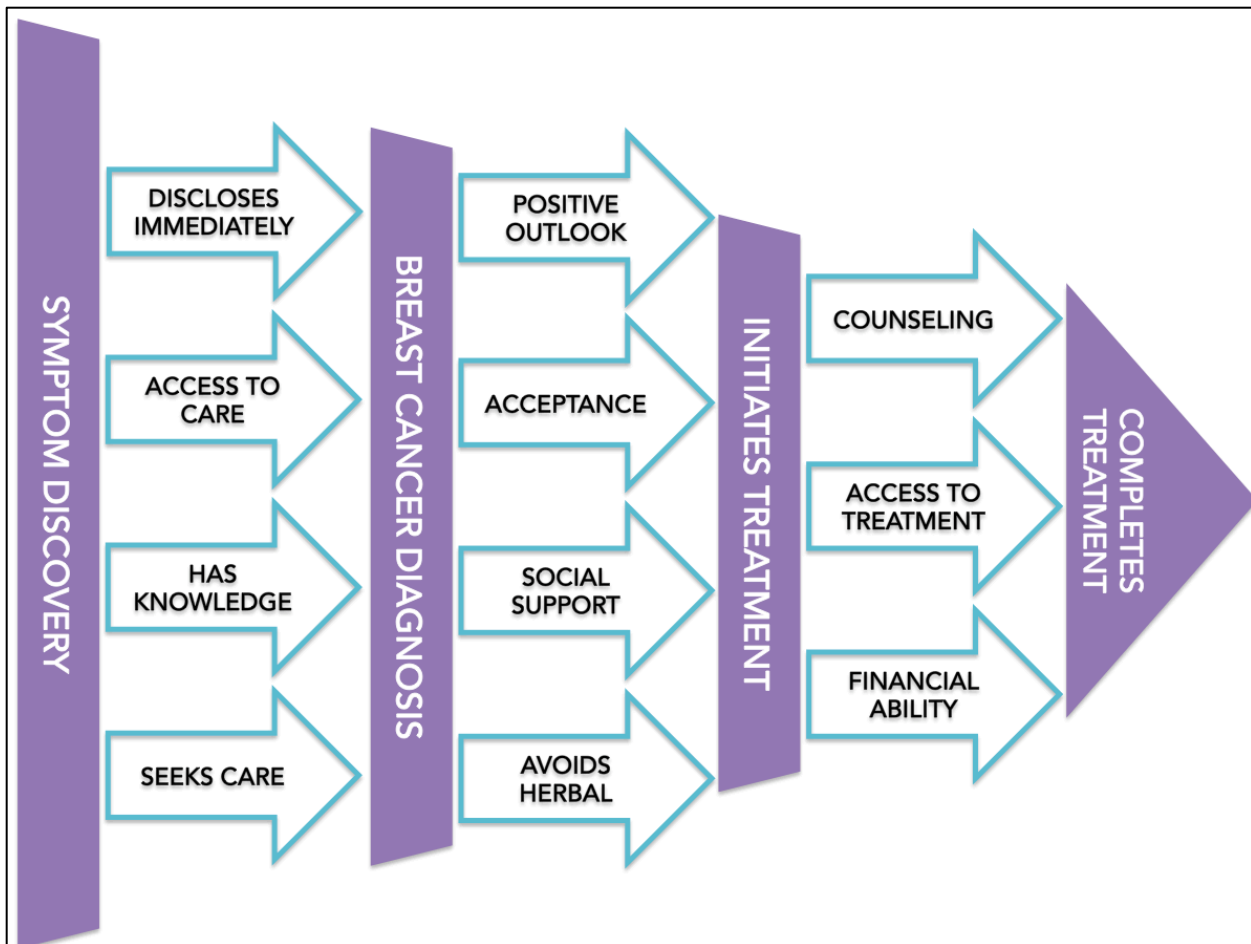


Figure 1: Conceptual Model of Findings

Participants contrasted their experiences, with those of other breast cancer patients in Uganda who fail to make it from one critical period to the next, either never engaging care or dropping out of care before completing treatment.

### **Symptom Discovery to Screening**

When participants shared their illness narratives, they began from the first discovery of symptoms. While the individual stories of symptom discovery differed across participants, key shared factors and behaviors emerged which led the women to seek care and screen for breast cancer. Most participants described they immediately disclosed their symptoms, had some knowledge of breast health, had access to care and wanted to engage with care quickly.

Most participants did not feel very knowledgeable about breast cancer before their experience with the illness; however they all noticed a change in their breast, such as a swelling or discharge, which they found to be concerning. This participant described a somewhat serendipitous way of learning about breast health:

***In a newspaper, it was written how to do breast self-examination. Immediately I examined mine, I found a swelling. I rushed to a clinic and when the doctor.***

This participant quote highlights a connection for this woman between gaining knowledge of breast health and immediately seeking care. The source of their breast health knowledge varied, some had been exposed to an awareness campaign, others knew of someone with issues with their breasts and a few participants were health professionals. For the participants who knew the signs of breast cancer, a few remember denying and/or fearing the significance of the symptom they were experiencing because of the stigma associated with breast cancer. All participants shared the idea that “*breast cancer=death*”, and that “*tampering*” with the breast is taboo.

A key behavior shared by almost all participants was immediate disclosure to a spouse, family member, or close friend when they noticed a symptom. For many of the participants, this was the first establishment of social support and gave participants the validation and encouragement to visit a clinic immediately.

***I touched..both breasts...,definitely there was something that is different from this one. So, I told my husband...I said...Do you feel anything different or am I imagining? He said; yeah, maybe. Then, he said why don't you go and see our general practitioner, a physician? Just let him have a look at it and advise.***

This quote highlights both spousal support after disclosure, but also key access to care which many participants had.

Not all participants described engaging in care immediately, some participants delayed seeking care for a few weeks, months or even years for a variety of reasons which included being busy with work and family. Only a few participants described a denial or dismissal of their symptoms being indicative of a health concern or even cancer, as a factor in delaying engagement in care.

***I had never seen a young person with cancer that is why I decided to leave it, it was painless. Since that time, it was like three years and it started paining me. I decided to go back to the hospital.***

However, participants shared how their illness experiences differ from other women in Uganda, even from the discovery of a first symptom. Participants shared stories of the majority of Ugandan women who either delay or fail to engage in care. Among a myriad of barriers such as lack of knowledge or lack of access to adequate clinics, participants shared that stigma around breast cancer is barrier even before a diagnosis has been made. Participants described that many women would rather avoid seeking care, because of a fear of breast cancer and the

accompanying stigma. This participant described how the internalized stigma, fear, impacts women concerns about their breasts:

*And others could be having the disease and they fear to go to hospital and seek medical help, they end up dying. So the stigma is still there.*

So, when participants described disclosing their symptoms and seeking care, they were overcoming the both self-stigma, fear, and social stigma surrounding breast cancer rather than remaining ashamed of their symptoms. Even having some knowledge that cancer is treatable and survivable, gave them the tools to continue to overcome the stigma and stay engaged with care.

### **Diagnosis to Treatment Initiation**

All the participants interviewed progressed from symptom discovery to being screened and positively diagnosed with breast cancer. While all participants had different illness paths, there were a few common facilitators, which led to their successful engagement with treatment and overcoming stigma associated with breast cancer: acceptance of their diagnosis, social support, a positive outlook and avoidance of herbal treatment.

All participants described the shock and devastation of a cancer diagnosis. Participants emphasized the strong social stigma: cancer is synonymous with death. Breast cancer patients internalize this stigma; they fear treatment, especially the removal of the breast, and believe they will not survive. This participant described her reaction when diagnosed:

*I felt it was the end of the world because I had not seen anyone who recovered from it.*

In the case of cancer, women may be internalizing the stigma in the form of fear associated with poor prognosis and high rates of cancer mortality. One form this internalization of stigma

manifested as was self-blame, participants described believing some behavior of theirs, such as using contraceptives, contributed to developing this disease. That internalized self-blame and shame may contribute to women delaying care engagement.

All participants described a pervasive negative social reaction to their diagnosis, even being told they would die by friends and family. All participants shared hearing these discouraging negative comments when others found out about their diagnosis. The social stigma of their diagnosis extended beyond them to being shamed for bringing cancer to their family, especially from their husbands family. Participants worried their children would not marry, as their family was labeled as “having cancer”. This social stigma leads breast cancer patients to be fearful and often inhibits engaging in screening and care.

***If the woman has grown up children, they will fear going for that screening because they will be found with cancer and it will also go to the children. When they are of marriageable age, people will say her mother had cancer. It is a stigma not only to the patient but also to the children...***

Also, all participants faced the immense social stigma of losing a breast and shame of not being a complete woman or wife with one breast. The stigma surrounding removal of a breast or even a biopsy of the breast, which is perceived to spread the disease, is enough to discourage women from seeking screening. Women internalize this stigma and fear of being without a breast, which can contribute to not seeking care. In addition, with the perceived certainty of their death, it is common for husbands of breast cancer patients to leave; sometimes men are even encouraged to leave their sick wives.

***I said some men think you are going to die. Why should he waste his time with you?...To some men, they see you as a walking corpse: you are not going to be of any help to him...They start disassociating with you.***

Participants shared this stigma is a reason women will delay screening for fear of the impact on their marriage and family. This participant shared what breast cancer patients often feel:

***So if they start thinking of cutting off the breast and what, they get scared. They get scared mostly because they fear losing their families, their husbands. I look at it as that is the biggest problem. They shy back, stay with their lump until the lump grows until it can't be contained anymore, that is why they report late and it gets so obvious and they can't keep it anymore, some even hide it from their husbands.***

Participants shared how many breast patients do not accept their diagnosis; rather they isolate themselves and fail to engage in treatment to avoid the risk social exclusion from the social stigma. After treatment, many participants described derogatory comments of being labeled or identified as having “one-breast”, even at their workplace. However, post-surgery, participants described using a prosthetic to avoid the social stigma.

The survivors described how they tackled the social stigma, avoiding self-stigmatization, of their diagnosis by coping in two key ways: accepting their diagnosis and maintaining a positive outlook, which was aided by surrounding themselves with positive social support. Participants described acceptance as a key element to care engagement because it signaled “feeling free” to pursue a treatment plan, face their cancer with courage and believe they had a chance of surviving. For many participants, acceptance came with a religious trust in their fate.

***After they have been told, one: some are still in denial. is it true? So I really need to start on this treatment for cancer? do I really have it? ...Until you accept it [your diagnosis]***

With these coping techniques, participants were able to start on medical treatment, despite the social pressure to pursue herbal treatment options. Almost all participants reported being encouraged to pursue herbal medicine at some point during their illness narrative as it is a more socially acceptable treatment, perceived to be more efficacious and allows women to keep their breast. Most participants described declining this treatment, especially when they could not meet with a person whose cancer was cured by the herbal treatments.

***Some could give you advice which you could not follow; why have you gone for surgery? That thing is bad you're going to die. Why don't you go for herbal? There is a***

***herbalist somewhere here...If you don't have firm mind, you may end up not going to the hospital.***

However, four participants reported using herbal medicine for a period of time, but they noticed their symptoms were not improving; all discontinued herbal treatment and re-engaged with modern medical options. They were often at a later stage in their disease and faced the stigma of having delayed their treatment.

Despite the stigmatizing comments participants faced as breast cancer patients, almost all interviewed survivors resolved to have a positive outlook. Participants all described needing to ignore the negative comments, which would erode their confidence or will to keep pursuing treatment. This personal resolve to maintain a positive attitude was described as crucial to not internalizing the social stigma by almost all participants. This participant described her approach to handling her diagnosis:

***I would say this cancer is painful, but I'm going to fight back. It is going to hurt me but I am also going to fight back. I am not going to allow it to get over me. That is one side. I decided to remain positive despite what has happened, but accept and move, flow with it.***

Participants emphasized that a positive outlook was easier with a circle of positive social support. Many had supportive husbands-who had encouraged them to be screened and stayed by their side through treatment. This support helped participants complete the challenging and long treatment of their cancer, overcoming the fear which surrounds so many of their peers with breast cancer.

## **Navigating Treatment Completion**

Even after participants started their treatment, they still faced stigma in order to complete their treatment. Participants described the difficulty of navigating the health system and affording their cancer treatment, facilitated by having good counseling from health providers and breast cancer survivors.

Participants all shared different treatment navigation stories; starting from screening through to surgery. All participants shared the difficulty in figuring out where to receive treatment, especially without draining their financial reserves. Many breast cancer patients discontinue their treatment due to the financial burden. The cost of cancer treatment paired with the poor prognosis, has led to a stigma of draining family resources. Some shared stories of private doctors, who exploited cancer as a “*cash cow*” and drained patients of money on inadequate treatment; the patient unaware of the Uganda Cancer Institute (UCI), the only public cancer treatment center in the country. This participant describes how breast cancer patients are delayed in the effort to seek treatment:

*And people are at times way-laid, I wouldn't call them quark doctors, but because they are money minded, they try to distort, to discourage people from going to UCI but I think they have the best services there. You may take time to get a surgeon, you may take time to get a doctor, but they usually get the best service because there are some instances when these private doctors tell patients that come I will give you chemo...{but don't}*

Most survivors describe eventually finding care at the UCI, which provides cancer treatment for free, if available. The difficulty of navigating treatment leads to major delays and often discourages patients from continuing. Participants all shared a determination to pursue their treatment no matter what their obstacles were.

Many participants shared the importance of good counseling from their physician, which included sensitive disclosure of a positive diagnosis, explanation of the disease, treatment course

and prognosis. Some shared stories of poor doctor-patient counseling with private doctors, non-oncologists; however once they got to the UCI, they were given proper counseling. The following participant described her doctor disclosing her diagnosis:

***[Doctor] said...the truth is you have cancer but it's curable and it's still at stage 2. Its early stage of 2, you still have a chance to live just do the needful go to the right doctor go to cancer institute don't listen to anybody who will tell you otherwise...***

For this participant, being told she had a curable early stage cancer was critical to remaining hopeful and committed to pursuing treatment.

In addition, some participants had assistance with navigating treatment from a breast cancer survivor, which was critical to getting correct information about treatment and having someone to ask questions, which aided continued care engagement and remaining hopeful of survival. Almost all participants are (or have been) members of UWOCASO and devote time to help current breast cancer patients navigate the system, because they know how crucial this is to staying with treatment to completion. While all the participants I spoke with considered themselves survivors, they shared that not all women who complete treatment are willing to identify as survivors or speak about their illness.

## **DISCUSSION**

This qualitative study begins to address a gap in research identified by Sharma et al. about barriers to breast cancer and impact on women's engagement in cancer care services, specifically addressing critical social factors highlighted by other researchers.<sup>10</sup> This study uncovered how stigma associated with breast cancer impacts care engagement throughout the illness experience for survivors in Uganda. The thematic analysis results showed how stigma not only delays women from engaging in care early, but also discourages women from remaining engaged with

care through to treatment completion. These findings concur with previous research from sub-Saharan African countries, expanding the understanding of how stigma impacts care engagement.

This study provided further support of the Koon et al. findings for the importance of social support, especially from spouses, family members and breast cancer survivors for engaging in care early and remaining in care.<sup>6</sup> Our findings also show that social support was not common for all breast cancer patients in Uganda, especially from husbands. However, when social support was present, it was a facilitator for women to engage in cancer care services. Expanding on the findings from Koon et al., study participants shared how they create their “pockets” of social support determined to ignore discouraging and negative influences so they could remain hopeful and successful with treatment.

The study findings demonstrate the need for stigma reduction programs for women diagnosed with breast cancer in Uganda. Stigma has been a significant barrier to engaging in care, which accompanies the other institutional and financial barriers. Due to the stigma associated with the mere word cancer, interventions aimed at reducing fear of breast cancer could help to reduce stigma and promote cancer care engagement. One method to reduce fear would be to elevate the role of cancer survivorship and advocacy programs. The more women hear the stories of survivors, the less cancer would be associated with fear and death.

The findings suggest a need for stigma reduction interventions across the entire course of the cancer care continuum. To improve screening behaviors, widespread awareness campaigns are needed which can be strengthened by survivor testimonials and informed by continued research in the area. These campaigns need to reach all areas of Uganda, rural and urban, not just people living in Kampala. In addition, like other health education efforts, there should be campaigns for

children and men, as well as women. Unanimously, participants shared how crucial awareness is to initial care engagement; they drew examples from success garnered from HIV campaigns in Uganda.

Additionally, more support is needed for patient navigation and adequate counseling to ensure women complete treatment. UWOCASO offers patient navigation and counseling services at several clinics in Kampala. The findings illustrate how critical these services are to care engagement, so these services should be scaled-up both at clinics in Kampala and beyond to regional referral hospitals.

Lastly, training for health care providers is needed to increase educating patients about breast self-examination (BSE), conducting clinical breast exams and sensitively disclosing a breast cancer diagnosis. Given the burden of stigma associated with the diagnosis, similar to HIV, it is critical to disclose positive test results and subsequent treatment options with sensitivity and care, especially when related to surgery. By better understanding the impact a diagnosis has on a patient, a trained health professional can inform a patient and discuss treatment in a manner that is not stigmatizing, but rather inviting of better engagement. Thus, survivor-advocates can assist in training health care providers by providing their perspectives on what messages they heard from providers that helped them to engage optimally in care.

### **Study Limitations**

This was a small exploratory study with a sample limited to Kampala, Uganda. While some participants were from other areas in Uganda, participants were largely from the capital city. Also, the sample was limited to women who had survived breast cancer, an outcome not common in Uganda. These considerations impact the generalizability of the data, as the

experiences of these 20 survivors may not represent those of all breast cancer patients in Uganda. However, participants were from diverse backgrounds within Uganda and varied on characteristics such as age, stage of diagnosis, and length of survival.

Many in our study population were members of UWOCASO, some of whom were breast cancer advocates and educators. This might bias their responses, as these women have overcome stigma, engaged in care successfully, and feel comfortable speaking publicly about their experiences. These survivors' experiences of stigma may differ from survivors who are not willing to identify as a survivor or speak about their experiences.

While most women in Uganda are diagnosed in stage 3 or 4, our study population was primarily diagnosed in stage 1 and 2, given our remission inclusion criteria. This is another potential source of sampling bias, as women diagnosed late frequently do not make it to remission or survivorship. It is likely women diagnosed in later stages experience more stigma than those diagnosed earlier. However, this bias was introduced due to the serious ethical concern of speaking to patients who presented late about their health seeking behavior, especially when their survival was uncertain. We felt setting the inclusion criteria at 1 year of remission, set a survival threshold at a minimum for a study population of survivors, while remaining sensitive to the ethical considerations.

All interviews and analysis were conducted in English, which further limited the sample population. While English is a national language in Uganda, participants reported several different first languages, the most common being Luganda. While this is potentially a barrier to eliciting meaning-rich qualitative data, participants seemed comfortable expressing their experiences in English. Further research with non-English speaking populations could address this limitation.

## **Conclusion**

This study opens a more in-depth examination of stigma associated with breast cancer and the impact it has on cancer care engagement in Uganda. The findings from this qualitative study are consistent with research on barriers to early detection in other sub-Saharan African countries. Hopefully, this study serves to encourage further research with aims to improve early detection, treatment engagement and completion for women with breast cancer in low-resource settings. This growing burden of mortality associated with breast cancer worldwide can be stemmed with increased resources for cancer care and evidence-based interventions, which include accounting for key psychosocial barriers, such as stigma.

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## APPENDIX A: Semi-Structured Questionnaire

DEMOGRAPHIC QUESTIONS	
Age	Number of Children
Martial Status	Length of time breastfeeding
Primary Language	Family History of Cancer
Religious Affiliation	Date of Diagnosis
Education Completed	Stage of Diagnosis
Place of Work	Date of Cure (Remission)
Location of Cancer Treatment	

Tell participant you are interested in hearing about their illness experience through symptoms, diagnosis, treatment and remission.

(Note for Interviewer: Probe further with each question to really understand how they were feeling at each stage in the illness)

- Tell me about when you first noticed a change in your health.
  - Did you share this symptom with a friend or family member?
  - Why or why not?
    - What was their reaction and/or advice?
      - How did you respond to this?
- Tell me about your experience in seeking care?
  - Can you share how your symptoms progressed
  - What motivated you to seek care at that time?
  - Can you share where you sought care
  - Why did you choose this location over another?
    - Can you share about what happened at this initial visit?
    - How did the health care provider or traditional healer respond to your concerns?
    - Can you share how you remember feeling?
  - What was the outcome of the visit?
  - Can you share any barriers you faced to seeking care?
    - How did you overcome these?
- (If not mentioned already) Tell me about when you were diagnosed with cancer?
  - Can you share what you initial reaction?
  - (If not mentioned: ask about if they were alone or with companions, what was the doctors attitude)

- (If not mentioned already) Can you share when you disclosed your disease to a friend or family member?
  - What that experience was like and how did you decide when to do this?
- Tell me about your experience through treatment?
- Tell me about your experience being cured and cancer free and any relapses?
- Overall, during your illness, what were you biggest challenges or barriers seeking the care necessary to overcome breast cancer?
- In general, how do you think early detection, treatment, and overall outcomes can be improved for women's cancers in Uganda?
  - Have you participated in any awareness or education outreach aimed at promoting early detection?
  - If so, can you share about that experience?
    - What impact do such interventions have?
  - (If a UWOCASO advocate) Can you share about your experience becoming an advocate and working with breast cancer patients?
    - What do you see as the primary barriers to women engaging with care?
    - How do you think these can be overcome?
  - Any other suggestions or input you would like to add about your experiences with breast cancer in Uganda?