

Community knowledge, attitudes and health-seeking behaviours towards breast cancer and early detection practices in Western and West-Nile Regions of Uganda

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Abstract

Background: Breast cancer remains the most common malignancy and a leading cause of cancer-related mortality among women globally and the second leading cause of cancer among women in Uganda. In Uganda, despite ongoing efforts to decentralize cancer prevention and early detection services, most breast cancer cases are still diagnosed at advanced stages. This study explored community knowledge, attitudes and health-seeking behaviours toward breast cancer and early detection practices in the Western and West-Nile regions of Uganda through the lenses of both the health professionals and the communities.

Methods: An exploratory qualitative design was employed, using five key informant interviews and eight focus group discussions conducted among healthcare professionals and community members in Arua and Mbarara health regions. Participants were purposively selected based on their involvement in breast cancer care or residence in the study areas. Data were collected using semi-structured interview guides, audio-recorded, transcribed verbatim, translated into English and analysed using manifest content analysis. Coding was performed both inductively and deductively to generate themes and sub-themes.

Results: Attitudes and health-seeking behaviours toward breast cancer were influenced by individual, community and health system factors. Individual factors included knowledge and awareness about breast cancer, detection of breast abnormalities and sociodemographic characteristics such as age, education and childbirth history. Exposure to breast cancer survivors and perceived personal risk also motivated health-seeking behaviour. Community-level influences included fear generated by witnessing others suffer or recover from breast cancer. Participants emphasised that awareness campaigns and access to trained health workers were key facilitators for early screening, while lack of knowledge and misconceptions hindered timely health-seeking.

Conclusion: Findings highlight that limited breast cancer awareness, misconceptions and sociodemographic disparities significantly affect women's health-seeking behaviours for

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breast cancer in Uganda. Exposure to breast cancer survivors and targeted health education were found to positively influence screening uptake. Strengthening decentralised breast health education programs, training of primary healthcare workers and community health extension workers can enhance early detection and improve outcomes.

Keywords: *breast cancer, health-seeking behaviour, awareness, early detection, Uganda, qualitative study*

Introduction

Globally, breast cancer is the most common malignancy among women, representing approximately 11.6% of all new cancer cases in 2022 (about 2.3 million new cases) and accounting for 23.8% of all cancers in women, with an estimated 15.4% contribution to global cancer mortality [1–3]. In many high-income countries (HICs), one in eight women develops breast cancer during a lifetime, making it a major public health burden that has overtaken lung cancer as the leading cause of cancer among women [2, 4].

The factors associated with the high prevalence of breast cancer include reproductive and hormonal influences such as early menarche, late menopause, nulliparity, older age at first childbirth and reduced breastfeeding [5, 6]. Genetic predispositions such as BRCA1 and BRCA2 mutations, lifestyle factors, including obesity, alcohol use and physical inactivity, and the use of exogenous hormones further contribute to the disease burden [7]. The consequences of breast cancer are far-reaching affecting women's physical, psychological, social and economic wellbeing, and posing a significant financial strain on families and health systems, especially in low- and middle-income countries (LMICs) [8, 9].

In sub-Saharan Africa (SSA), breast cancer is the second leading cause of cancer-related morbidity and mortality among women after cervical cancer, with an estimated incidence rate of 33.8 per 100,000 women per year in the region [10, 11]. While the incidence of breast cancer in SSA remains lower than in many high-income settings, the case fatality rate is considerably higher, with pooled estimates of a 5-year survival average of only 40%–48% in SSA compared to over 90% in most HICs [2, 12]. The high mortality in SSA reflects late-stage diagnosis, limited access to diagnostic and treatment services and weak health system capacity for comprehensive cancer care [13, 14].

In Uganda, the age-standardised incidence rate of breast cancer is approximately 21.3 per 100,000, with a mortality rate of 10.3 per 100,000 women [1, 15]. Projections indicate that by 2040, more than half of all new breast cancer cases globally will occur in LMICs, like Uganda [16]. The disproportionately high mortality in Uganda is largely due to disparities in access to breast health education, limited availability of diagnostic services and suboptimal access to appropriate treatment modalities, coupled with poor decentralisation of cancer services [17]. In Uganda, comprehensive oncology care is centralised, with the Uganda Cancer Institute (UCI) serving as the primary national referral centre for cancer diagnosis, treatment and training. Despite the recent policy recommendations to establish four regional cancer centres in the Western, West-Nile, Northern and Eastern Uganda, regional- and district-level health facilities still have limited capacity to provide early breast cancer detection and diagnosis, resulting in delays and reduced accessibility, especially in rural and underserved communities [17]. Despite these ongoing efforts, 70%–80% of breast cancer cases in Uganda continue to be diagnosed at advanced stages, with 5-year survival rates as low as 20% [17, 18]. Late detection is attributed to limited awareness, low prioritisation of breast health education in health facilities and the absence of consistent community-based screening and awareness programs [19].

Despite the inadequate number of mammography services in low-income countries, including Uganda, breast self-examination (BSE) remains a simple and low-cost alternative method to promote early detection awareness; however, its uptake in Uganda remains low. A recent study found that only 23% of women in Arua City knew how to perform BSE [20]. Similarly, low rates are observed across SSA with Ghana reporting 37.6%, 24.4% in Nigeria and 15% in Cameroon [21, 22]. In Ethiopia, BSE practice varies widely: 51.4% in Adama [23], 45.8% in Gondar [24] and 6.25% in Adawa [25]. Understanding and strengthening breast health literacy at the primary care level through health education on BSE, clinical breast examination, breast ultrasound and mammography where available, is therefore critical. In parallel, understanding and addressing systemic barriers such as late presentation, low community awareness and inadequate provider capacity remains essential for reducing mortality.

Therefore, this study explored community knowledge, attitudes and health-seeking behaviours toward breast cancer and early detection practices in the Western and West-Nile regions of Uganda and strategies to strengthen breast cancer early detection in the communities through the lenses of both the health professionals and the communities.

Methods

Study design and setting

The study utilised an exploratory descriptive qualitative design among participants (health workers and adult community members) in Western (Mbarara) and West-Nile (Arua) health regions – regional referral hospital catchment populations. The Uganda Ministry of Health (MOH) through the Communicable and Non-communicable diseases technical working group provided administrative clearance of this study. Ethical approval was obtained from the UCI research ethics committee (REC) (Reference number UCI-2024-136), and the permission to conduct the study was provided by the Uganda National Council for Science and Technology (Reference number: HS5551ES). In Uganda, UNCST is the national regulatory body for research, while RECs or the Institutional Review Board (IRB) provide localised, institutional research and ethics review. Therefore, UNCST issues final research permission/registration, while RECs/IRBs handle the detailed research and ethical review.

Study populations

The study population for the key informant interviews (KIIs) included healthcare professionals who were involved in the care of patients with breast cancer during the time of data collection and had consented to participate in the study. In addition, the study population for the focus group discussions (FGDs) included consenting adult community members aged 18 years and older in the rural and urban areas of the selected health regions – Western and West-Nile.

Sample size determination

The sample size was determined by data saturation and was reached at five KIIs and eight FGDs.

Sampling and selection of study participants

KIIs (five): A convenient sample of five was purposively selected, comprising two officials from the MOH Non-communicable diseases (NCD) department, and three UCI officials that included a clinician directly involved in care of breast cancer patients, the person responsible for training/capacity building at UCI and a representative from the community cancer services department.

Four FGDs were conducted in each health region. Two FGDs (one male only and another female only) from urban setting and the other two were from a rural setting (one male only and another female only). Arua city and Mbarara city were considered urban settings for the Western and West-Nile regions, respectively. The most rural district of the remaining participating districts in each study region (as defined by the respective UCI Regional Cancer head) was selected as the site for the rural FGDS (one male only and another female only). Ntungamo and Koboko districts represented the rural communities of the Western and West-Nile regions, respectively. Adult community members aged 18+ years who were residents in the project districts for at least 3 months were recruited from the central market (in the Cities) and the trading centre (in the rural district). Each FGD had 5–7 members of the same sex with representation of both young adults and older adults in 3 age groups (i.e., 18–24, 25 ± 44 and 45+ years old).

Data collection tool and procedure

The qualitative data from the KIIs were collected using an interview guide that was specifically developed for this study by the principal investigators and written in English. Similarly, qualitative data from the FGDs were collected using a FGD guide, also developed for this study by the principal investigators and written in English and translated into the local languages.

The study tools were pretested prior to data collection and minor iterations were made based on the feedback from the exercise. The principal investigator and trained professional research assistants explained the study purpose to all participants and obtained written informed consent before data collection. With participants' permission, interviews and discussions were audio-recorded, and field notes were taken

to capture nonverbal cues, contextual information and participants' expressions to enrich the data. No personal identification details were captured to maintain participant confidentiality.

Data management and analysis

All audio-recorded data were transcribed verbatim. FGD audio-recorded data were simultaneously translated from the local language into English during transcription. Data analysis involved a combination of inductive and deductive coding using a pre-developed codebook with a priori codes. Codes were changed and emerging codes were added through the intercoder reliability process and only if deemed necessary by the whole coding team. The codebook was finalised and applied to all the transcripts, prior to final approval, using a consistent set of codes and a uniform understanding of how to apply them. A coder reliability check was performed on 10% of coded transcripts selected at random throughout the coding process. Once the data was coded, the team synthesised the data under parent codes to identify and analyse relationships between differently coded data. The codes were entered into a master Excel sheet where all text relating to the code was assigned the respective code. Manifest content analysis (that is themed as said by the participants) was applied, leading to themes and sub-themes. Each summary text was read several times while being analysed to ascertain the group (code) that it belongs to.

Quality control and assurance

The principal investigators employed various strategies, such member checking and peer debriefing, to enhance the trustworthiness of findings. Thorough documentation, transparent reporting and maintenance of an audit trail of the research process to contribute to the dependability of results were employed. The research also adhered to established qualitative methodologies and employed systematic data analysis techniques.

Results

Characteristics of participants

A total of 61 participants were included in the study, comprising five KII and 56 community members who participated in FGDs. Five key informants were staff members from the UCI and officials from the MOH working in the NCD department. Eight FGDs were conducted across Mbarara city, Arua city and the districts of Ntungamo and Koboko, representing urban and rural communities, respectively. In each region, two FGDs were conducted in urban settings with one male and one female, and two in rural settings, one male and one female. Each FGD comprised 5–7 members, with participants stratified by age groups: 18–24, 25–44 and 45 years and above, to ensure representation of both younger and older adults (Tables 1 and 2).

Theme 1: Availability and dissemination of breast cancer information

Participants consistently reported that **national-level data on breast cancer is limited**, with the MOH relying heavily on global estimates rather than local data. One MOH official stated:

'Information on breast cancer within the country is limited. We don't get information from the Cancer Institute regarding what is happening... if it was shared, we would disseminate further' (KII_MOH_002).

This lack of data hampers the ability of policymakers to identify trends, monitor progress or develop targeted interventions. Another participant noted:

'We have two sources of information: global estimates and the data we may collect from screening camps or District Health Information Software (DHIS) reports. But even that is not always sufficient to guide our interventions' (KII_MOH_002).

At the UCI, dissemination primarily occurs through information, education and communication (IEC) materials such as booklets and flyers. These materials are distributed to patients and health facilities, but participants highlighted limitations in quantity, scope and language accessibility.

'The information materials are not adequate in quantity. Even where you have them, distribution is limited... we need to make use of other avenues like churches and community meetings' (KII_ Oncologist_UCI).

Resource constraints and logistical limitations were commonly cited as barriers to effective dissemination:

'We try to develop materials for patients, but resources are limited. Not all our materials are available in local languages, and outreach efforts are restricted' (KII_ Cancer Surgeon_UCI).

Theme 2: Programs supporting breast cancer awareness

Several organisations actively support breast cancer initiatives through awareness campaigns, screening and psychosocial support. Notable actors included Hospice, St. Augustine's Hospital, the Center for Disease Control, Cancer Society, Uganda Women's Cancer Support Organization and Uganda Protestant Medical Bureau. Community members highlighted the role of mobile outreach programs:

'I have seen Hospice's car moving around the village, telling people about breast cancer and where they can go for checkup and treatment' (FGD_Mbarara City).

Key informants emphasised collaboration between community-based organisations and UCI to provide oversight, clinical expertise and patient referral pathways:

'Different organizations target breast cancer awareness in communities, but the UCI provides oversight and guidance to streamline care' (KII_ Cancer Surgeon_UCI).

Despite these efforts, participants acknowledged that programs are often fragmented and event-based, limiting consistent coverage across regions:

'While there are various awareness programs, there is no systematic approach for breast cancer prevention and early detection' (KII_ Oncologist_UCI).

Theme 3: Community knowledge and misconceptions about breast cancer

Community knowledge was generally low, and misconceptions were prevalent. Participants frequently associated breast cancer with visible breast abnormalities, spiritual causes or moral transgressions. One participant explained:

'Some believe breast cancer can be caused by tight bras, family planning or even exposure to coins' (FGD participant).

Limited awareness of male breast cancer and biomedical risk factors such as family history, alcohol use and obesity was noted:

'People usually think breast cancer only affects women. Men hardly discuss it, so cases may go unreported' (KII_ Oncologist_UCI).

Theme 4: Detection, screening and prevention

Sub-theme 4a: Limited knowledge of screening methods

Participants reported minimal knowledge of breast cancer detection methods. Most believed that screening occurs exclusively at health facilities through ultrasound or mammography, with few women performing BSE:

'Most women think breast cancer can only be detected at health facilities using ultrasound' (FGD participant).

Table 1. Social demographics of key informant participants and settings of the community FGDs participants.

Social demographics of the KII participants				
IND No	Sex	Organisation	Title	Number of years in service
001	Male	MOH	MoH NCD Department	20
002	Male	MOH	MoH NCD Department	25
003	Male	UCI Mulago	Oncology Surgeon	14
004	Female	UCI Mulago	Nurse in breast cancer screening	16
005	Male	UCI Mulago	Medical oncologist	19
Settings and regions of the community FGD participants				
		West-Nile Region	Western Region	Total
Urban setting	Male	1 (Arua city)	1 (Mbarara city)	2
	Female	1 (Arua city)	1 (Mbarara city)	2
Rural setting	Male	1 (Koboko district)	1 (Ntungamo district)	2
	Female	1 (Koboko district)	1 (Ntungamo district)	2
Total FGDs		4	4	8

Table 2. Themes and Sub-themes from the KIIs and FGDs.

Theme	Sub-theme/Code	Illustrative Quotes
Availability and dissemination of breast cancer information	National-level data gaps	'Information on breast cancer within the country is limited. We don't get information from the Cancer Institute... if it was shared, we would disseminate further'. (KII_MOH_002).
	Reliance on global estimates	'We have two sources of information: global estimates and the data we may collect from screening camps or DHIS reports'. (KII_MOH_002)
	IEC materials limitations	'The information materials are not adequate in quantity... we need to make use of other avenues like churches and community meetings'. (KII_Oncologist_UCI)
Programs supporting breast cancer awareness	Community outreach programs	'I have seen Hospice's car moving around the village, telling people about breast cancer and where they can go for checkup and treatment'. (FGD_Mbarara City)
	Collaboration with UCI	'Different organisations target breast cancer awareness, but the UCI provides oversight and guidance to streamline care'. (KII_Cancer Surgeon_UCI)
	Fragmented program coverage	'While there are various awareness programs, there is no systematic approach for breast cancer prevention and early detection'. (KII_Oncologist_UCI)
Community knowledge and misconceptions	Sign and symptom focus	'Women we only go to check our breasts when they realize there is an abnormality say with their nipples; to see if it's a disease or not'. FGD_Mbarara 'Pain can influence you to go to the hospital, if trained person is there in the hospital, if the village health leader has told people to go to the hospital". FGD_Koboko 'If you touch your breast and feel it is too hard or you feel some lumps, you will be motivated to go to hospital for checkup'. FGD_Mbarara City 'If you are a breastfeeding mother, and when you press your breast, and instead of milk coming out, there comes blood or some liquid resembling stale milk, then you will know that you have to visit a health worker for checkup. And if you go there early, you might be treated and the disease gets cured'. FGD_Mbarara City
	Male breast cancer awareness	'People usually think breast cancer only affects women. Men hardly discuss it, so cases may go unreported'. (KII_Oncologist_UCI)
	Biomedical risk factor awareness	'Few people know about family history, alcohol use or obesity as risk factors'. (FGD participant)

Continued

Table 2. Themes and Sub-themes from the KIIs and FGDs. *Continued*

Detection, screening and prevention	Limited knowledge of screening methods	'Most women think breast cancer can only be detected at health facilities using ultrasound'. (FGD participant)
	Misconceptions about prevention	'Some believe allowing men to suckle breasts prevents cancer'. (FGD participant) 'Some believe breast cancer can be caused by tight bras, family planning or even exposure to coins'. (FGD participant)
	Health worker-led education	'Preventive services are event-based; integrating screening into routine reproductive health services would strengthen early detection'. (KII_Cancer Surgeon_UCI)
Health system factors influencing care	Availability and accessibility	'In Uganda, you can't do mammograms because it is only possible in Kampala. People from Kisoro, Karamoja, Arua have no access'. (KII_ Oncologist_UCI)
	Affordability	'The cost of mammography and transport to distant facilities is high, so women often delay screening'. (FGD participant)
	Post-diagnosis behaviour	'Some patients consult herbalists or prayer centres after diagnosis because they believe cancer is incurable with modern medicine'. (KII_Cancer Surgeon_UCI) 'Others disown the results and seek treatment from witch doctors or herbalists' FGD_Arua City 'Go to prayer centre for healing' FGD_Mbarara
Strategies to improve screening uptake	Community awareness	'We need to use community meeting places to reach women, not just the District Health Office'. (KII_Cancer Oncologist_UCI)
	Integration into routine care	'Integration ensures sustainability and increases screening rates'. (KII_Cancer Surgeon_UCI)
	Male involvement	'Male involvement encourages women to seek screening and treatment promptly'. (KII_Cancer Oncologist_UCI)
	Health financing and technology	'Strengthening local funding and investing in portable screening technologies could increase access in remote communities'. (KII_ Oncologist_UCI)

Sub-theme 4b: Misconceptions about preventive measures

Community members described a mixture of correct and incorrect preventive strategies. While some mentioned healthy diets, exercise and early treatment, others cited culturally rooted practices, such as:

'Some believe allowing men to suckle breasts prevents cancer' (FGD participant).

Healthcare providers emphasised training women on BSE and conducting awareness campaigns, although national preventive programs remain fragmented:

'Preventive services are event-based; integrating screening into routine reproductive health services would strengthen early detection' (KII_Cancer Surgeon_UCI).

Theme 5: Health system factors influencing breast cancer care**Sub-theme 5a: Availability and accessibility**

Geographical distance and the centralisation of specialised care at UCI were frequently cited barriers. Basic diagnostic tools, such as ultrasound, are available up to Health Center IV, but mammography and biopsy services remain centralised:

'In Uganda, most people can't do mammograms because it is only possible in Kampala. People from Kisoro, Karamoja, Arua have no access' (KII_Cancer Oncologist_UCI).

Sub-theme 5b: Affordability and cost of services

High out-of-pocket costs for screening and treatment discourage timely care:

'The cost of mammography and transport to distant facilities is high, so women often delay or do not undergo screening' (FGD participant).

Participants suggested subsidising screening services and integrating them into national health insurance schemes to reduce financial barriers.

Sub-theme 5c: Health-seeking behaviour post-diagnosis

Fear, stigma and reliance on alternative care delay treatment initiation:

'Some patients consult herbalists or prayer centres after diagnosis because they believe cancer is incurable using biomedical treatment' (KII_Cancer Surgeon_UCI).

Community exposure to survivors positively influenced health-seeking behaviour:

'Seeing someone survive breast cancer motivates women to seek early care' (FGD participant).

Theme 6: Strategies to improve screening uptake

Sub-theme 6a: Community awareness and education

Participants emphasised culturally sensitive health education targeting both men and women, using community structures such as Village Health Teams (VHTs), churches and local councils:

'We need to use community meeting places to reach women, not just the District Health Office' (KII_Oncologist_UCI). 'Information should reach down to the lower health facilities ... including holding out reaches FGD_Arua city'. 'The best channel of communication could be through the churches, radios, LCs, VHT, Mosques' FGD_Koboko.

'Using churches, VHTs to communicate cancer information'. FGD_Mbarara City.

Participants mentioned that having a breast cancer survivor in the community served as another factor motivating individuals to seek breast cancer services. 'Fear of others suffering from it makes you go for screening' FGD_Mbarara 'When somebody has healed in the community and we have all seen her then if my breast gets a complication, I can also go to hospital to be treated after all I have seen someone gets healed' FGD_Arua City.

Sub-theme 6b: Integration into routine health services

Integrating screening into maternal health, family planning, HIV services and NCD clinics was recommended to improve uptake:

'Integration ensures sustainability and increases screening rates' (KII_Cancer Surgeon_UCI).

Sub-theme 6c: Male involvement

Participants highlighted the importance of engaging men to support women's attendance at screenings and adherence to treatment:

'Male involvement encourages women to seek screening and treatment promptly' (KII_Oncologist_UCI).

Sub-theme 6d: Health financing and technology

Sustainable domestic financing and portable diagnostic technologies were suggested to improve access, particularly in rural areas:

'Strengthening local funding and investing in portable screening technologies could increase access in remote communities' (KII_Oncologist_UCI).

Discussion

The findings of this study reveal that community knowledge about breast cancer is generally low and characterised by misconceptions and cultural beliefs. This limited understanding of breast cancer symptoms may hinder early health-seeking behaviours, leading to delayed diagnosis and poorer outcomes. The misconception that breast cancer only affects women was also evident among participants. Similar misconceptions have been reported in Uganda and other African contexts, where male breast cancer is rarely acknowledged [26]. Participants also attributed breast cancer to causes such as tight bras, exposure to coins and cultural transgressions, which lacks evidence for such association. These findings are consistent with earlier studies in Ghana, Nigeria and Uganda [27, 28]. Such misconceptions highlight the persistence of traditional explanations for disease and the limited reach of biomedical health education. This lack of awareness among community members may contribute to underreporting and delayed diagnosis among men who develop the disease. Overall, the findings underscore the urgent need for culturally sensitive health education programs that demystify breast cancer, promote awareness of early symptoms and include both men and women. Tailored interventions that integrate community beliefs and engage local leaders could enhance acceptance and uptake of early detection services.

The study revealed that community members possessed limited knowledge about breast cancer detection. Most participants believed that breast cancer could only be detected at health facilities through ultrasound examinations, with minimal awareness of other screening methods such as mammography, clinical breast exams and the importance of breast health awareness through self-breast exam. Similar findings have been reported in Uganda and other low-resource settings, where knowledge of modern screening methods remains low due to inadequate health education and limited access to screening services [22, 28]. Participants also held several misconceptions about preventive measures and unsupported beliefs, such as 'allowing men to suckle breasts of their spouses' as a preventive practice. These findings are consistent with studies from Ghana and Nigeria, where similar myths persist [27, 29]. Overall, the findings underscore the urgent need for comprehensive and continuous breast cancer education, community-based screening programs and capacity building for health workers to educate and train women on self-examination techniques and breast cancer risk reduction measures such as avoiding alcohol drinking, eating healthy and balanced diet, engaging in regular physical activity, maintaining health weight and breastfeeding. Strengthening these interventions could enhance early diagnosis, improve treatment outcomes and reduce the growing burden of breast cancer in Uganda.

While diagnostic and treatment options for breast cancer exist in Uganda, access remains unevenly distributed, skewed to the capital city, Kampala. Diagnostic services for breast cancer in low-resource settings are constrained by inadequate infrastructure and equipment [30, 31]. On the other hand, participants identified surgery, chemotherapy, radiotherapy and palliative care as the main options. However, these services remain concentrated in the capital city and the two new regional cancer centres and a few private hospitals, with radiotherapy being available only at UCI-Kampala. This restricted access reflects the centralisation of specialised oncology services in Uganda, as highlighted in previous studies [15, 32]. The concentration of treatment services in urban centres like Kampala continues to exacerbate disparities in access, particularly for women in rural areas who face logistical and financial barriers to care [33]. These findings underscore the need to expedite the decentralisation of cancer diagnostic and treatment services, improve access to clinical breast exams, mammography and ultrasound scans availability and strengthen referral systems.

In this study, knowledge and awareness emerged as critical determinants of health-seeking behaviour, similar to findings from Kenya and Ghana where limited awareness was associated with delayed presentation [27, 30]. Detection of breast abnormalities such as pain, lumps or nipple discharge was another key trigger for seeking care. This reactive approach aligns with previous studies in Uganda and Nigeria showing that most women seek medical attention only after noticing symptoms, often at advanced stages [28, 29]. This highlights the need to promote proactive health-seeking behaviour through regular screening rather than symptom-driven consultation. Exposure to breast cancer survivors in the community was found to positively influence health-seeking behaviour by instilling hope, awareness and resilience to adhere to the recommended treatment. Similarly, community experiences of illness have been shown to shape individual perceptions and encourage

preventive health behaviours [26]. Fear and witnessing recovery stories can thus act as motivators for screening uptake. Additionally, tailored interventions alongside survivor-led awareness programs may improve attitudes and promote timely health-seeking behaviour for breast cancer.

Geographical accessibility and the presence of trained healthcare workers were found to be strong motivators for seeking breast cancer services. Women living near health facilities or connected to healthcare providers were more likely to undergo screening than those in remote areas. This finding aligns with previous research in LMICs, where distance to health facilities and availability of diagnostic services significantly determine health-seeking behaviour for cancer care [17, 34–36]. Limited accessibility contributes to delayed presentation and late-stage diagnosis, consistent with findings in SSA [26].

The affordability of breast cancer screening and treatment services emerged as a crucial determinant of utilisation. Studies conducted in Kenya and Tanzania reported that financial barriers, including out-of-pocket costs for mammography and chemotherapy, limit service uptake [37, 38]. Thus, health financing reforms that subsidize or integrate breast cancer services within public health insurance schemes or state-funded schemes could improve access and continuity of care.

Participants' responses after diagnosis often reflected denial, stigma or reliance on alternative care such as herbalists, witch doctors and prayer centres. Sociocultural beliefs and fear of cancer diagnosis often lead to delayed presentation and nonadherence to biomedical treatment in African settings [27, 39, 40]. Denial and misperceptions about the incurability of cancer hinder early treatment initiation, underscoring the need for psychosocial and community-based interventions to address these misconceptions.

To improve screening uptake, awareness campaigns through community structures such as VHTs/community health extension workers, places of worship like churches and local councils were seen as essential for improving knowledge and reducing stigma. This is consistent with a systematic review finding [41], which indicated that community-based health education and survivor-led advocacy improve participation in screening programs. Moreover, integrating breast cancer screening into routine care such as maternal health, family planning and HIV services was also recommended. Evidence supports that such integration increases screening rates and ensures sustainability, particularly in resource-constrained health systems [42].

This study identified multiple barriers to breast cancer screening categorised under individual, community and health system factors. At the health system level, insufficient emphasis on early detection interventions and limited funding for awareness and early detection were major obstacles. Similar findings have been documented in Kenya and Nigeria, where preventive services for NCD, including breast cancer, receive inadequate prioritisation compared to curative care [43, 44]. The low level of awareness about breast cancer symptoms, risk factors and available screening services emerged as a dominant barrier. Knowledge deficits and misinformation contribute to low participation in breast cancer screening [29, 45]. Enhancing community education through mass media and primary healthcare engagement could bridge this gap. Sociocultural barriers such as stigma, privacy concerns, religious restrictions and gender power dynamics also strongly influenced women's decisions to seek screening. The perception that cancer is incurable, fear of divorce and shame related to breast exposure were frequently mentioned. Cultural taboos and negative attitudes toward cancer deter women from seeking early screening [27, 46].

Furthermore, financial constraints were a major deterrent to screening, especially given the high costs of mammography and transport to distant facilities. Women often prioritize household responsibilities over preventive care, especially when approval from spouses is required [34, 47]. To address these challenges, there is a need to integrate low-cost breast cancer screening options such as clinical breast exams into routine primary care and community-level outreach while equipping local health centres (HC III and IV) with basic diagnostics and clear referral pathways. This requires nationwide capacity building, culturally sensitive community cancer education and sustained funding, backed by targeted operational research and a national population-based cancer registry to generate evidence to guide interventions.

In summary, barriers to breast cancer screening in Uganda are multifaceted, encompassing systemic inadequacies, low awareness, sociocultural beliefs and financial limitations. Addressing these challenges requires a comprehensive, multilevel strategy focusing on improving public awareness, decentralising screening services, training healthcare providers, providing psychosocial support and strengthening health policies that prioritize preventive health interventions.

Conclusion

This study explored community knowledge, perceptions and practices related to breast cancer, as well as barriers and facilitators to early detection in the Western and West-Nile regions of Uganda. The findings reveal that despite increasing awareness of cancer as a public health issue, community knowledge about breast cancer remains limited and clouded by misconceptions, cultural beliefs and misinformation. Many community members associate breast cancer with visible symptoms, spiritual causes or moral transgressions, while few understand biomedical risk factors or the importance of early screening. Health-seeking behaviours were largely reactive and symptom-driven, with women often seeking care only after detecting abnormalities, typically at advanced disease stages. Attitudes toward screening were influenced by fear, stigma, limited awareness and sociocultural norms that restrict open discussions about women's health. Male involvement and exposure to survivor stories emerged as strong motivators for positive health-seeking behaviour.

At the health system level, significant structural and organisational challenges persist. Screening and diagnostic services such as mammography and biopsy remain centralised at tertiary institutions, particularly the UCI, while most regional and lower level facilities lack capacity for early detection and referral. Financial constraints, long travel distances and limited human resources exacerbate inequities in access to breast cancer care. Preventive services are fragmented, with inadequate integration into existing primary healthcare programs such as maternal, HIV or NCD clinics.

The study underscores the urgent need to decentralize breast cancer screening and diagnostic services, strengthen health system capacity and enhance community awareness through culturally sensitive, gender-inclusive and sustainable interventions. A decentralised model that empowers primary healthcare providers and leverages community structures can play a critical role in improving early detection and reducing the burden of breast cancer in Uganda.

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Conflicts of interest

The authors do not declare any conflicts of interest.

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Consent to publish

All authors read and approved the final version of the manuscript prior to its submission for publication.

Ethical approval

Uganda Ministry of Health through the Communicable and Non-communicable diseases (CONCOD) TWG provided administrative clearance of this project. Ethical approval was obtained from the UCI research ethics committee (Reference number UCI-2024-136) and the Uganda National Council for Science and Technology (Reference number: HS5551ES).

Author contributions

JA: study design, data collection, analysis and interpretation and drafting original manuscript, SNG: conceptualisation of study, collection, analysis and review of manuscript, VKK: data collection and review of manuscript, and SO and RO: drafted and reviewed the original manuscript. RK: data collection, analysis and interpretation of data. JK and NM: critical review of manuscript. All authors read and approved the final version of the manuscript.

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