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The perspectives of healthcare providers, traditional healers, and other key informants on the late diagnosis of breast cancer in northern Tanzania: a qualitative study

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Abstract

Background Breast cancer (BC) is the most common cancer among women in Tanzania and has one of the highest mortality rates worldwide due to late-stage diagnosis and suboptimal treatment. The role of traditional healers in late-stage diagnosis has not been widely studied. We aimed to identify the barriers to early BC diagnosis in Tanzania and possible solutions by interviewing healthcare providers (HCPs), traditional healers (THs), and other key informants (KIs).

Methods We used phenomenological qualitative study design. We administered six open-ended qualitative questions to 20 HCPs (including 10 doctors and 10 nurses), 10 THs, and 9 KIs in rural and urban community settings in the Kilimanjaro region. A focus group discussion with 8 THs was also conducted. The questions explored perceived reasons for late diagnosis of BC, the initial reaction of patients who presented with a noticeable breast changes and reasons for visiting a health facility after the disease had advanced. Participants were recruited after their working hours. Data were analyzed using thematic approach and NVivo 12 software.

Results The findings were synthesized into five themes to explain late diagnosis: (1) HCPs and THs have limited knowledge and misconceptions about the causes, signs, and symptoms of breast cancer; (2) patients experience stigma (3) treatment is expensive and difficult to access; (4) patients perceive barriers based on myths, misperceptions and spiritual beliefs; and (5) HCPs and THs often blame each other for ineffective treatment and delays in effective treatment. The participants also provided suggestions to reduce delays in diagnosis and treatment, including enhancing knowledge and awareness among THs and HCPs to help them recognize the signs and symptoms of BC through education campaigns, addressing the cost of access to care and treatment, addressing stigma associated with BC, and developing collaborative efforts between HCPs and THs.



Conclusion In this study, limited knowledge, misconceptions, stigma, access and cost was observed as barriers across all groups. Raising community awareness and improving understanding of BC is crucial in reducing misconceptions and stigma. Future collaboration between healthcare providers and traditional healers could be beneficial in the development of strategies to recognize the early signs and symptoms of BC and promote pathway referral to care.

Keywords Healthcare providers, Key informants, Traditional healers, Breast cancer, Late diagnosis, Tanzania, Africa

1 Introduction

In Tanzania, breast cancer (BC) is one of the leading causes of cancer-related death among women [1]. According to the International Agency for Research on Cancer's (IARC) Global Cancer Observatory data, the incidence of BC in Tanzania is steadily increasing. By 2030, the number of new breast cancer cases is expected to rise by 82%, with breast cancer deaths increasing by 80% [45]. Notably, late-stage diagnosis is a major challenge in managing BC as it decreases the chance of curative treatment and increases the risk of mortality [1–4]. Reasons for delayed presentation of BC are multi-factorial and include poor BC knowledge and awareness among women and healthcare providers, limited access to and affordability of diagnosis and treatment, and the preferential use of traditional healers (THs) [2, 4–8].

Nearly 70% of the population in Tanzania receives healthcare from THs, who are often the first point of contact for patients seeking medical treatment [9, 10]. THs in Tanzania are accessed widely for a range of health problems, such as hypertension and diabetes [11]. The overall number of THs in Tanzania is more than 75,000, with a resident-to-traditional healer ratio of 1:350–400 [12, 13]. In contrast, there is one medical doctor for every 33,000 people [13]. The costs of traditional medicine are reportedly lower than the costs of Western biomedical treatment [14]. Furthermore, 70.5% of patients report the use of traditional healer services due to poor service delivery of biomedical healthcare, strong credibility of traditional practices, strong cultural identity and influences, and poor health status [2, 10, 15].

Despite the popularity of THs and the limitations of healthcare services in Sub-Saharan Africa, healthcare providers (HCPs), including doctors and nurses, play a crucial role in the early detection, diagnosis, and treatment of BC as well as palliative care for patients with BC [16]. A recent qualitative study with Tanzanian participants was conducted to identify reasons for advanced-stage BC at the time of diagnosis [2]. Participants reported that a lack of adequate knowledge and awareness of BC and misconceptions. Participants faced barriers with their local primary healthcare providers, including symptom mismanagement and delayed referrals for diagnostic evaluation, financial hardships, fear and stigma of cancer, and the use of traditional medicine is a common reason for advanced disease presentation [2].

Similarly, a qualitative study in Tanzania found that a lack of cancer training among HCPs contributed to a lack of knowledge of cancer diagnosis and treatment [17]. In many Low middle Income Countries (LMIC) settings, HCPs lack sufficient cancer knowledge, skills and resources to effectively diagnose and manage patients with early symptoms, spread knowledge, and positively influence patients' attitudes and behaviors [17, 18].

In addition to healthcare providers and traditional healers, key informants (KIs), such as local government leaders, community leaders (village, street, and religious leaders), regional medical officer, district medical officer, reproductive health coordinators, and policy-makers, play a crucial role in shaping public health behaviors. Their position as leaders in the community enables them to serve as role models and champions for health promotion and to specifically target vulnerable populations that may be difficult to engage through conventional outreach methods. For instance, community religious leaders, who often provide spiritual guidance within healthcare institutions, also play an essential role in public education, social support, and advocacy, particularly during critical health situations [19–21]. Given their significant influence and ability to communicate effectively with diverse communities, KIs are instrumental in dispelling myths and misconceptions about diseases, including cancer, on a global scale. Thus, they are uniquely positioned to provide invaluable insights into effective strategies for health communication and community engagement and to ultimately improve health outcomes within the populations they serve. Previous research has focused on individual health-seeking behaviors or the effectiveness of healthcare intervention. However, there has been limited attention to KIs' contribution to shaping public health messages, dispelling myths, and mobilizing communities.

In summary, prior research indicates that HCPs, THs, and KIs are influential in the diagnosis and treatment initiation of BC. Understanding the perspectives and attitudes towards BC among HCPs, THs, and KIs, in Tanzania is crucial for devising effective BC control strategies and improving the quality of life of women with BC. Our study aimed to gather insight into the perspectives and roles of these providers and KIs concerning BC awareness, diagnosis, and treatment to identify common themes and patterns in their influences on changes in health behavior and disease prevention. This approach provides a nuanced understanding of the social dynamics that affect breast cancer outcomes and highlight the potential for integrated healthcare strategies that leverage the strengths of these providers. Additionally, this study addresses a significant gap in the literature by exploring the roles and influences of KIs in health behavior change and disease prevention within the Tanzanian context. By integrating the perspectives of these providers and community leaders, this study aims to provide a more comprehensive understanding of the social dynamics that affect health outcomes to ultimately inform practices and policies that leverage these influential figures to enhance community health initiatives.

2 Methods and materials

2.1 Study design

A phenomenological study design was used to explore the determinants of late-stage BC diagnosis. Phenomenological research seeks to describe experienced phenomenon and to obtain a view of peoples motivations and actions [46–48]. Specifically, in this study we focused on examining the perceptions and experiences of HCPs, THs and KIs with regard to BC and barriers to early-stage diagnosis. The analysis was based on twenty interviews. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [49] (See Supplemental Appendix 1).

2.2 Study setting

The study was conducted in urban and rural settings across five districts Moshi Municipal, Moshi Rural, Rombo, Hai and Mwanga of the Kilimanjaro region of Tanzania (See Fig. 1). The region has a total population of approximately 1.4 million people [22]. Nine health care facilities were included: one tertiary zonal hospital, one public regional referral hospital, four district hospitals in rural and urban Kilimanjaro, and three health centers in urban and rural Kilimanjaro. The selected health facilities were representative of all levels of health facilities that receive and refer patients with cancer. Additionally, based on information provided by the Kilimanjaro region's TH coordinator, one district, Mwanga, was selected for a focus group discussion (FGD) with THs because of the reported large number of THs in that district.

2.3 Recruitment of participants

Health Care Provider who had at least a diploma in the health sciences field and who had been providing care to cancer patients at an oncology clinic for more than a year were purposively selected to participate in the study. Health care providers were identified from the health care facility database, and THs were purposively selected by the Regional Traditional Healers Coordinator. Efforts were made to include KIs from various socio-economic backgrounds, geographic locations, and community segments to capture a broad spectrum of views and experiences related to BC awareness and prevention. KIs, including local government leaders, community leaders (village, street, and religious leaders), regional medical officer, district medical officer, reproductive health coordinators, and policy makers were selected by the director for non-communicable diseases and the Unit of Churches, an organization comprising all major religious denominations in the Kilimanjaro region. All participants were contacted by the first author, Elizabeth Msoka [EM], to introduce the study and determine their interest. THs aged 18 years or

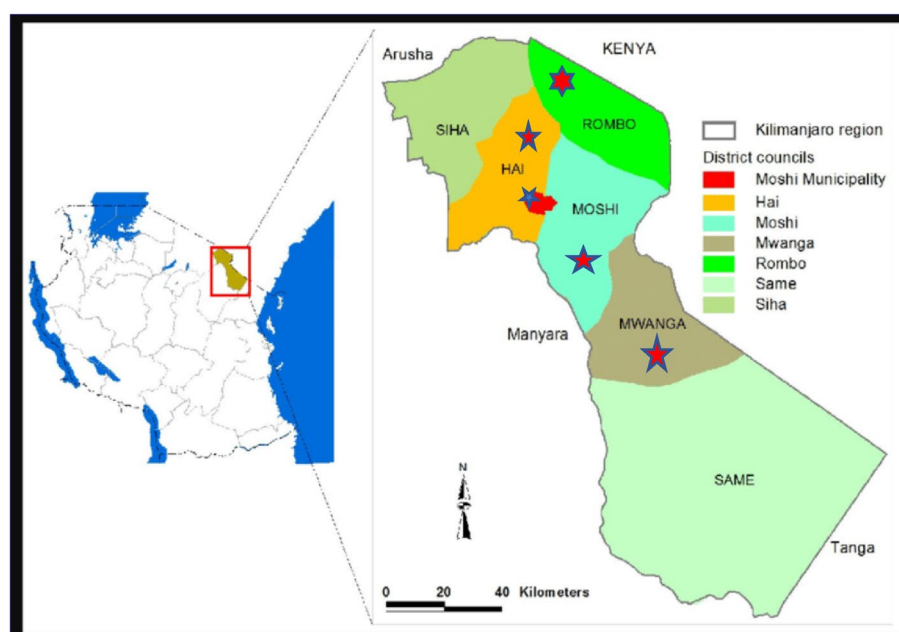


Fig. 1 Location map showing 5 Districts with stars indicating where data was collected in Kilimanjaro Region
Source: https://www.researchgate.net/figure/Location-map-showing-sustainable-land-management-SLM-project-area-in-Kilimanjaro_fig1_276499039

older who were registered with the Ministry of Health and who had treated patients with BC in the past were contacted via telephone by a TH coordinator who described the study and determined their interest. All interested individuals who consented to participate and spoke the local language (Swahili) or English fluently were included in the study.

2.4 Interview guide development

The research team, EM and Perry Cyril (PC) developed different interview guides for HCPs, KIs, THs and patients. During the development of the interview guides, the team made several revisions. A semi-structured interview guide was used to balance open-ended exploration and focused questioning during the interviews. The guide was developed by the team following a thorough literature review and initial KI interviews. It was first developed in English and then translated to the local language (Swahili) to better facilitate communication with the participants. To identify interview themes, the questions focused on the HCPs', KIs' and THs' perceived reasons for late diagnosis of BC, the initial reaction of patients who presented with a noticeable breast change, and reasons for visiting a health facility after the disease had advanced (for the interview guide, see Supplementary Table 1.).

The same interview guide (Supplementary Table 1) was used for all HCPs, THs, and KIs with differences in probing questions based on the responses from the participants. Specifically, the interviewer provided an initial question or prompt and then probed for additional information based on the participant's response, which allowed for further exploration of relevant topics unique to each participant. For both the IDIs and FGD, the interviewers first gathered socio-demographic data from the participants and then asked about their knowledge of risk factors for BC and other factors found to be important in other studies [2, 23, 24] (See Supplementary Table 1.).

Towards the end of the interview, the interviewers asked what the participants thought about THs and traditional medicine with respect to managing BC.

All interviews with HCPs and THs and some interviews with KIs were conducted within the hospital setting. Interviews with the other KIs were conducted through the phone while THs were conducted in their communities during the day and lasted 45–90 min. All interviews were tape-recorded, transcribed verbatim and translated into English. To enhance the range of experiences and perspectives, data were collected in different districts, including rural and urban areas. All information was de-identified during transcription. Transcripts and translations were cross-checked for accuracy and consistency. Appropriate written notes were also taken during the interview to capture non-verbal communication.

Five pilot interviews were conducted prior to the commencement of the actual research. This allowed the researcher to address any problematically worded questions or issues with the interview structure while also identifying a few potentially confusing questions. The data collected in this interview were not included in the analysis.

2.5 Data collection

In-depth interviews and FGDs were conducted in person from November 2022 to March 2023, and each participant was compensated (5000 Tanzanian shillings (US Dollar 1.9)) for transportation to the interview location. After providing written informed consent

to participate in the recorded interview, the participants were interviewed in Swahili by two researchers (EM and PC). Both interviewers had previous experience in qualitative research conducted in Swahili. The study participants, interviewers and note takers all spoke Swahili. All interviews took place in private environments. However, with face to face interviews the presence of noisy distractions (speedy motorcycles passing along the road) and a cold environment affected the comfort of our participants during the interview. These factors did not affect the recordings. The interviews were audio-recorded using digital recorders.

The interviewers prompted the participants using the interview guide until all the questions listed were covered. Each interview lasted 60–90 min. Qualitative data were collected from HCPs working in these health facilities through the Heads of their units and their coordinators and through phone contact, with interviews conducted in their private offices after working hours. Data were collected from THs in community settings through identification by the gatekeeper and TH coordinator. The THs interviews were conducted in their selected place of preference, mostly were in their homes during mid mornings. For Key Informants (KIs) data were collected both from the hospital and community settings through phone contact, with interviews conducted from either hospital or community settings through face to face or phone calling after working hours.

The audio recordings were stored in the researcher's laptop that had a password lock at all times. After transcription the data was transferred using encrypted devices, and was kept safe in the NVivo software. We reached data saturation after 20 IDI interviews with HCPs, 10 IDIs with THs, 9 IDIs with KIs and 1 FGD with 8 THs. We defined saturation as no new salient themes could be identified, and data start to repeat, indicating that an adequate sample size has been reached [25].

2.6 Data analysis

Two social scientists (PM and RM) and a PhD student who were fluent in both Swahili and English performed data collection, transcription, and translation. First, all audio-recorded interviews were transcribed verbatim in Swahili; then, a supervisor and a mentor who were experienced with qualitative study cross-checked the transcripts for errors. The transcripts were then translated into English and the data were anonymized.

Over a one year period, the data were analysed thematically, allowing for an open and exploratory approach to data analysis and enabling the researchers to capture a wide range of participants' perspectives and experiences [26, 27]. After all of the translated transcripts and data were imported into NVivo software version 12 for Mac for computer-based data coding, we identified meaningful units of data and assigned descriptive codes to capture the essence of each segment. We subsequently looked for additional recurring patterns, concepts, or ideas across the data, and similar codes were grouped into potential themes. Then, the themes were reviewed and refined through an iterative process of organizing related codes and ensuring coherence within each theme. The researchers assigned clear and meaningful names to each theme that accurately represented their content, provided a detailed description of each theme, and identified specific quotes that exemplified each theme. After identifying the five major themes, the authors extracted commonly stated suggestions from all stakeholder interviews regarding how to reduce delays in BC diagnosis. These suggestions were used to develop a set of potential interventions to mitigate delays in diagnosis and treatment in Tanzania.

2.7 Ethical considerations

Ethical approval was obtained from local and National ethical review boards of Tanzania. Participants provided written informed consent to participate after reading a participant information sheet. All documents were kept private and confidential. The audio-recorded interviews were reviewed only by the transcribers, principal investigator, and supervisors. Each participant was identified by a specific code number rather than by his or her name.

3 Results

3.1 Participant characteristics

Forty-seven in-depth interviews (IDIs) were conducted with the participants (20 with HCPs, 9 with KIs, and 10 with THs), and 1 focus group discussion (FGD) was conducted with 8 THs.

In total, 50 participants were included in the study, three withdrew their consent due to lack of time as they lived far away and would have needed to catch transport early (Fig. 2).

Among them, 20 were HCPs: 10 doctors (6 male and 4 female) and 10 nurses (7 female and 3 male). The average age of the HCPs was 39.15 years (range, 27–56 years). Most HCPs were 16 (80%) Christian, 13 (65%) unmarried, and all were employed in urban facilities. Of the 18 THs included, 14 (78%) were male, and 4 (22%) were female. The

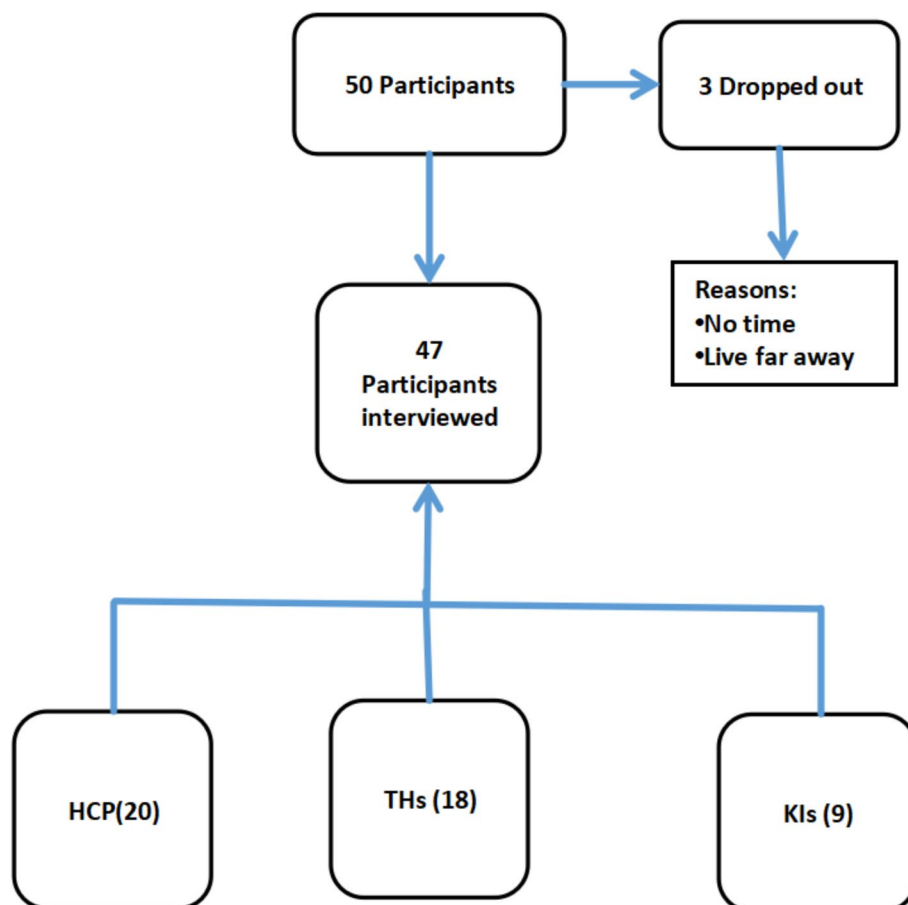


Fig. 2 Flow Chart Showing Participants Included in the Study

average age of the THs was 61.45 years (range, 33–95 years); most 14 (78%) were married, half 6 (33%) had never attended school, most 14 (78%) were Muslims, and the majority 13 (72%) were located in rural settings. The remaining 9 participants were KIs (3 female and 6 male); this group included 2 TH coordinators, 2 religious leaders, 2 policy makers, 1 Regional Medical Officer, 1 District Medical Officer, and 1 regional reproductive health coordinator. The average age of the KIs was 57 years (range, 43–69 years), and the majority 8(89%) of the KIs were employed in urban facilities, all were married and almost all were educated. The average age of THs was much older than that of the KIs and HCPs. However, a larger proportion of THs and KIs were married compared to the HCPs (See Table 1).

All variables are expressed as n (frequency, %) unless otherwise noted.

3.2 Five themes underlying the barriers to early diagnosis of breast cancer

To obtain the perspectives of HCPs, THs, and other KIs regarding barriers to the early diagnosis of BC in Tanzania and to identify possible solutions, we carefully analyzed the interview transcripts to determine underlying themes. Five main qualitative domains were identified. These were limited knowledge and misconception, stigma, access and cost of treatment, barriers based on myths, misconceptions and spiritual beliefs, ineffective treatment and strategies to reduce delays in diagnosis and treatment (Fig 3.). Figure 3 shows knowledge and beliefs impact behaviours leading to late diagnosis of breast cancer.

Table 1 Social-demographic Characteristics of Healthcare Providers, Traditional Healers and Other Key Informants

Social-Demographic Characteristics	Healthcare Providers (n = 20)	Traditional Healers (n = 18)	Key Informants (n = 9)
Mean Age (range) (years)	39.15 (27–56)	61 (33–95)	57 (43–69)
< 39	12 (60%)	1 (6%)	0
40–59	8 (40%)	10 (56%)	8 (89%)
> 60	0	7 (39%)	1 (11%)
Gender			
Male	9 (45%)	14 (78%)	6 (67%)
Female	11 (55%)	4 (22%)	3 (33%)
Marital Status			
Married	7 (35%)	14 (78%)	9 (100%)
Unmarried	13 (65%)	4 (22%)	0
Educational Level			
Never attended school/Informal training	0	6 (33%)	0
Primary school	0	10 (56%)	1 (11%)
Secondary/Tertiary education	20 (100%)	2 (11%)	8 (89%)
Employment Type			
Employed	20	18	8 (89%)
Unemployed	0		1 (11%)
Religion			
Christian	16 (80%)	4 (22%)	6 (67%)
Muslim	3 (15%)	14 (78%)	3 (33%)
Other religion or no religion	1 (5%)	0	0
Residence			
Urban	16 (80%)	5 (28%)	6 (67%)
Rural	4 (20%)	13 (72%)	3 (33%)

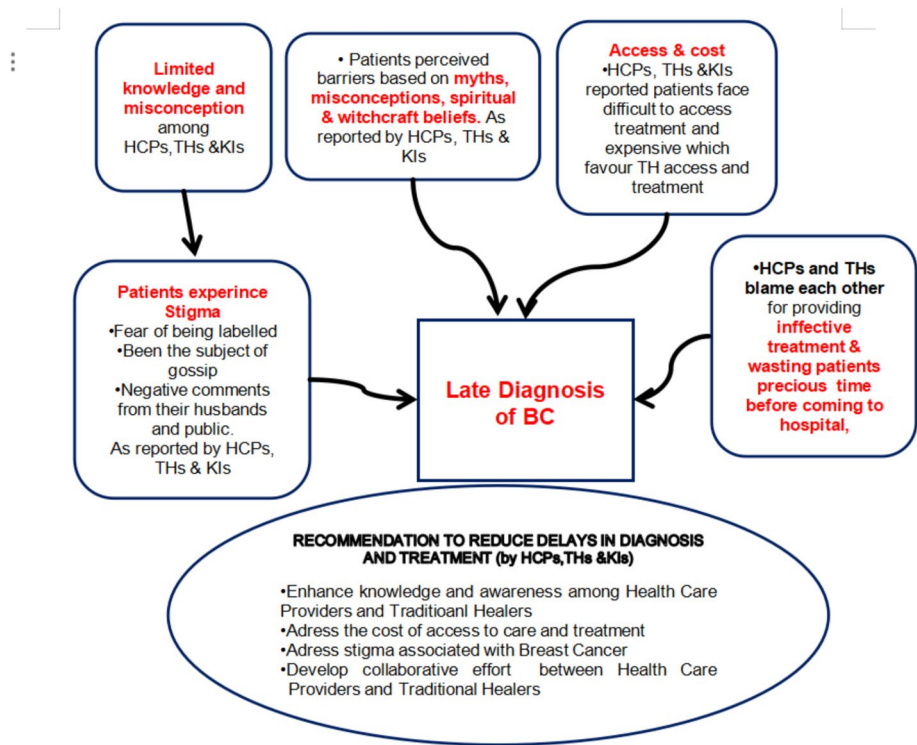


Fig. 3 Conceptual framework of barriers to early diagnosis of breast cancer derived from the qualitative themes

Table 2 Themes That Emerged from All Stakeholders

SNO	THEMES
	HCPs, KIs and THs have limited knowledge and misconceptions about the causes, signs and symptoms of BC
	Patients experience stigma
	Treatments are difficult to access and have high costs
	Patients perceive barriers based on myths, misconceptions and spiritual beliefs
	HCPs and THs often blame each other for ineffective treatment and, consequently, delayed effective treatment

A summary of identified themes emerged from HCPs’ THs’ and KIs can be found in [See Table 2].

3.3 HCPs have limited knowledge and misconceptions about BC causes, signs and symptoms

The first theme, that participants have limited knowledge and misconceptions about BC causes, signs and symptoms, refers to the finding that participants involved in the study lack comprehensive understanding and may hold incorrect beliefs about what causes BC and how to recognize its symptoms.

Most HCPs knew the causes and risk factors for BC such as lifestyle factors including behaviors and exercise. For, example:

“...the source of breast cancer is not yet known, but there are causes that speed up breast cancer; one of them is the lifestyle that we live. People eat food that has a lot of oil or fat, and they don’t do exercise. Another cause is by inheriting it from one’s

parents. You can get cancer from a lack of exercise, and another cancer is caused by inheriting it from your parents..."

However, there were some striking misconceptions. Multiple participants i.e., HCPs (55%, n = 11) falsely believed that contraceptives, hormonal replacement therapy, as exemplified by the following interview excerpts. For example:

"...cooking oil, the family planning pills. You know these pills we are using for preventing pregnancy are dangerous to our health...I think they are not good for our health it is because we need them so as we may not get many children, but they are dangerous, I think so..."

One HCP expressed his concern about how HCPs could misdiagnose cancer:

"...Because you may see a patient is having wound and think that is chronic wound while it is a cancer.....other health providers don't know patient may have cancer...patients still will not ask what kind of disease is this....the breast becomes swollen.....then patients will be told that is a cyst..."

Additionally, another participant expressed concern regarding cancer misdiagnosis:

"...The major reasons are the use of artificial foods there are the most common causes of these cancers today...so I can see these artificial foods that we eat are the major causes for these cancers..."

Moreover, some participants believed that BC can be transmitted by touching patients. For example:

"...This is because the care that we provide to our patients is all about chemotherapy. Therefore, in the process of giving out chemotherapy, there is a danger for me to get breast cancer...after touching the patient, within 48 hours you can get cancer..."

Health care providers expressed their fears about the growing prevalence of BC among women in Tanzania. For example:

"...Breast cancer is the disease that affects most women; when you see a woman with breast cancer; you must be scared and feel that even me, I may get breast cancer because I am a woman..."

Together, these perspectives show that there is a wide range of beliefs and perceptions about the causes of and risk factors for BC.

Limited knowledge and misconceptions regarding the signs and symptoms of BC also result in misdiagnosis. Nurses reported being unsure about how to identify the symptoms of BC and stated that symptoms are sometimes mistaken for symptoms of mastitis, often resulting in unnecessary courses of antibiotics and further delaying a BC diagnosis. For example:

"...To tell the truth, I don't understand much about this [breast cancer]. Because while we are here at the clinic, people come with some sort of a swelling, and when you take them to the doctor, they look at it and say that it might be cancer, and so they refer the patient to KCMC. Another doctor might just say that it is a swelling, and they do an incision on it, and later on it vanishes..."

Additionally, a HCP said,

“...Another reason is poor knowledge on the side of healthcare workers in primary-level care centers. Therefore, you go to a dispensary or a district hospital; sometimes people will misdiagnose it, and [the patient] might be diagnosed with mastitis, given an antibiotic, and sent home. So if we ask the patient why you come so late, they will say, ‘We have gone to the hospital 3, 4, 5 times, and we have been treated with antibiotics or some other medication and sent back home’...”

HCPs also explained how they learned about BC and its treatment. Although they reported being trained partly at university and partly through clinical experience, there were overall indications of limited education. This was mentioned by one HCP participant:

“... Cancer needs to be taught thoroughly in medical schools, especially in our medical schools here in the country. There must be a special rotation in the oncology unit where doctors can get more experience from the patients...”

3.3.1 THs have limited knowledge and misconceptions about BC causes, signs and symptoms

Even though HCPs expressed notable misconceptions, the majority communicated correct BC knowledge. In contrast, the majority of THs did not know the causes of or risk factors for BC, with most of them believing that BC is an infection or can be caused by haggling. Similar to the HCPs’ misconceptions, the THs’ misconceptions were related to the false belief that BC is contagious and can be transmitted through direct or indirect contact (e.g., through clothes, spoons, cups) with BC patients. A TH said:

“...The person who is caring for a cancer patient also gets cancer. In that case, cancer is contagious. Even in the hospital, the person who is taking care of a cancer patient is given protective devices to prevent them from getting cancer...those who are caring for the patients must be watchful that they do not get it. They should always wear gloves when they are caring for them, and they should not share spoons or dishes. If the patient eats food and leaves some of it, you should not eat it but throw it away...”

Additionally, one TH said,

“...If a person who has cancer uses a brush to clean his feet or body, they must make sure that the brush is not used by another person. The thing is the bacterium is left in the brush, and so if a child or his wife comes and uses the brush, they will get the disease. Therefore, the patient who has cancer should use their own cups, spoons and plates...”

THs are trained by their ancestors or elderly people, such as grandmothers, and gain expertise in understanding, recognizing and diagnosing BC. Knowledge is sometimes passed from father to son. This was mentioned by a TH:

“...The grandma who raised me used to provide cancer medicines...I hear now that patients with this disease are taken to India. When my grandma used to provide medicines for cancer, such as of the spleen, breast, and kidneys, she would give all these medicines even though she was not a doctor. She was just someone who knew what leaf could cure what disease...that is what my grandma taught us...”

Another TH participant added,

“...I taught him [TH’s son] about various types and kinds of medicine. We would spend 40 days in the forest with me teaching him about each medicine and its function. If we find a tree pointing north, we leave it, but if it points east, we collect it...”

A knowledge gap exists among THs due to a lack of formal education and evidence-based training in cancer diagnosis and treatment. Some traditional healers rely on medical doctors to obtain cancer knowledge. For example:

“...I learn more about disease symptoms from my friends who are medical doctors. I work with them when I have patients who come to me with a diagnosis. It helps me to start them with my medicine...”

3.4 Patients experience stigma

HCPs, KIs and THs all considered stigma among patients to contribute to delayed BC diagnosis. Both self-stigma and societal stigmatization of BC lead some patients to fear revealing their symptoms to others, which causes delays in screening and treatment and hinders early diagnosis. All HCPs, KIs and THs cited negative ways in which BC patients were treated and looked upon by their husbands, family members and the community after revealing a diagnosis. A TH participant said,

“...Getting cancer is not a normal thing; they mock them. Some cancer patients have wounds, and family members treat them differently. Some of them are psychologically tortured, such as with insults and separation; some are isolated, for example, eating and sleeping alone in separate places and using separate plates, which are constant. Cancer patients, especially woman who suffer, face divorce. Some are left with children to care for while they are sick, and some are abused, such as by being bitten...”

One KI said,

“...But there are also some women who are worried about going for breast screening in that if they are found to have breast cancer, they will be depressed and not able to enjoy their lives, and they perceive that they will die...others hide themselves from the wide community because they feel shame, while using local herbs...”

Another KI participant added,

“...I cannot give direct evidence, but when you tell people about radiation treatment or an operation whereby they have to remove the whole breast, they feel like it is a scary thing, that it is abnormal to have a body part removed, and that they will look handicapped from removing a part of their body...”

Finally, a HCP participant said,

“...There is a lot of stigma because some of them believe that this is contagious. If I touch you, I will get cancer; if I help you at home, as your sister or husband or whoever, if I stay with you, I will get cancer. And you can see some of the women, they will even tell you that their husband runs away because he thought, you know, staying with them, he will also get cancer. So these things, they do exist, yeah...”

3.5 Treatments are difficult to access and expensive

HCPs, KIs and THs all reported that BC patients delay seeking biomedical hospital care and favor TH access and treatment due to the costs associated with transportation, medical evaluation and treatment. Both HCPs and THs described their patients' financial hardship and their struggle to obtain the money necessary to access healthcare, which contributes to delays in diagnosis. In addition, they mentioned that some of their patients had to travel from distant rural areas for necessary diagnostic investigations. For example a HCP participant said,

"...Even transport [is an issue] because these are people who travel 12 kilometres, which is a long distance to come here for the diagnosis... and we don't really have all the means because we have a lot of challenges regarding diagnosis equipment..."

Additionally, a KI said,

"...They told me that we can't afford the costs, so it's better to go for those herbs...so I don't know...but frankly, people like the ones who live in villages, the majority cannot afford [these hospital costs]...for example, she told me that biopsy test costs four hundred thousand..."

One KI participant noted that high costs are not specific to BC but also limit access to treatments for other diseases:He said:

"...In order to cut down costs, because it is not only for breast cancer but also for all diseases...[it is] better to promote health insurance for all people to join..."

3.6 Patients perceive barriers based on myths, misconceptions and spiritual beliefs

Several participants, primarily HCPs, KIs and some THs, reported perceived barriers among patients based on specific and often interrelated beliefs about patients with BC. These beliefs concerned the causes of BC and the effectiveness of various treatment options. Specifically, some patients believe that BC is caused by witchcraft, and as a result, these patients do not believe that hospital treatment is curative.

One HCP expressed his experience with patients:

"...We still have a few patients who don't believe in our treatment; they think of being bewitched, and so they go to the healers and get herbs. Some of them start [hospital treatment] and then stop because they do not trust them. They go and start the herbs for some time, and thereafter, they return to the hospital when they are too sick..."

KIs pointed out that the majority of cancer patients do not understand the causes of cancer and often present to traditional healers before seeking biomedical treatment. For example:

"...I believe that a lot of people believe that they got cancer as a result of being bewitched...most of them usually start with traditional healers before going to hospital...if they do not feel better, they return to hospital when it is too late...this belief is very widespread, and it is very deceiving..."

Both HCPs and THs consider patients' faith in God and related religious beliefs (e.g., the power of prayer to cure BC) to be barriers for early diagnosis and treatment.

They reported that patients trust they will be healed when they receive prayers. This was shared by a HCP participant, who said,

“...Some breast cancer patients go to church for prayers, they wash your breasts, etc. Some of them go to witch doctors for treatment, hoping to get cured, but the truth is that they don't get cured...”

This belief in prayer over traditional treatment was also noted by one TH:

“...I have a wife; she had cancer. She did not believe in traditional treatment. She wanted to go for prayers. There were pastors from Nigeria. She went there for 3 months, but it did not work. I gave her my treatment after that, and she is now okay...”

Some traditional healers believe that though they may not be able to treat the general misconceptions of patients regarding how BC is contracted; traditional medicines may still cure the disease.

For example:

“...Other people have bad superstitions...the trees are there so we can have medicine.... People who are religious believers do not believe in traditional medicine. A lot of disease can be cured by traditional medicine these days...”

3.7 HCPs, KIs and THs sometimes blame each other for administering ineffective treatment and, consequently, delaying effective treatment

The next most important theme was HCPs assigning blame to THs for administering ineffective treatments and wasting precious time before the patient comes to the hospital, having attempted traditional healing in futility. In turn, THs believe that biomedical treatments are ineffective, although THs still expressed a desire to collaborate with HCPs. From the HCP perspective, patients spend time and money on traditional treatments that will not cure the disease, and consequently, they seek care from the hospital when the cancer is already in an advanced stage, as noted by a HCP participant:

“...What we understand about traditional healers is that they try to deceive the patients; they say that they have medicine that can treat/cure cancer while they know that it is not true. The truth is that their medicines have not been approved, and patients spend a lot of money because patients trust them and use their medicine. They don't get cured, and they come to our cancer department at a stage when it is likely not possible to help them because it is too late to do much...”

However, traditional healers express their desire to collaborate with HCPs. He said:

“...One thing, health care providers should prepare seminars whereby we can meet together and get knowledge, we need more knowledge on breast cancer and other cancers in order to continue helping our patient...”

On KI also added and said:

“For example a doctor whom I consult always she gives me gloves that I use when treating my patients. I asked her if it would be possible for us to be meeting with her once a week so that we could exchange experience... This would be good because not all of us know about the signs of breast cancer. We should be told about how cancer

starts its origins e.t.c. we should also be told about the language that we should be using with the cancer patients. Not all of us traditional healers know how to talk to our patients. There are some people who receive patients but the language to use to talk to them makes patients wish they had never come. As you know, you could go to visit someone and the way they accept you... you feel comforted..."

He further stated that,

"...Patients who are in the ward are those with stage 4 disease. If you ask these patients, most of them will tell you that they have used traditional medicine. So if these herbal medications could actually help them, I don't think we could help them in the ward..."

In contrast, the majority of THs believe that pharmacological treatment provided by biomedical hospitals cannot cure BC. Instead, they believe that traditional medicine is more effective than hospital treatment, as stated by a THs participant:

"...A lot of people have been cured. Even Arabs, Indians, and even Americans come here. This watch I am wearing and the phone I have, I was given by Americans.... As long as it [cancer] hasn't been touched by hospital medication, I give them the treatment, and they will be cured..."

Some of the THs explained that BC patients do not want to go to hospitals due to long waits for treatment and diagnostic investigations that make them feel burdened. They therefore end up mistrusting hospital procedures. This was expressed by a KI who attended a cancer clinic. He revealed that the long delays in obtaining test results further delay BC diagnosis:

"...Some of the patients, they refuse to [go to the] hospital for evaluation. Some say they have been sick for a long time, and they don't want to go to the hospital because it takes very long to go through the hospital process until you get a diagnosis..."

Finally, THs suggest that the most effective way to address delayed diagnosis is for biomedical providers to obtain test results more promptly. As a TH participant stated,

"...One suggestion here is that if the doctor decides to take the biopsy, he should get the results within two days... but you find that the patient waits a very long time for the results while she rots away..."

3.7.1 Suggestions to reduce delay

Building upon the insights gathered from the results section, where we explored the perspectives of HCPs, THs, and KIs about the barriers to timely BC detection and diagnosis, this subsection presents a range of actionable solutions. The participants identified a variety of possible interventions aimed at addressing the multifaceted challenges revealed in our analysis.

All HCPs, THs and KIs suggested educational intervention campaigns and programs to enhance awareness of BC symptoms, signs and risk factors and the benefits of early diagnosis as an approach to mitigate the increasing burden of BC in the region. They also noted the importance of using mother tongue languages, for example, Chagga, when discussing and providing education on BC because many local people are not able

to read or speak the local language (Swahili). Therefore, to deliver BC-related communications effectively, participants claimed that, language barriers should be accounted for. This was said by a HCP participant:

“...So we could also include these (what is breast cancer, signs and symptoms, risk factors, what are the treatment, etc.) in the posters or leaflets. Simple language is important to use; we can use the local language or the mother tongue language, the native language where people can read in their own language. They can be taught in their own language how they can examine their breasts, how if any change occurs, they can refer [to this educational material]...”

A HCP suggested that men should also be educated on BC:

“...Men should be more educated on breast cancer to help women come to the hospital and get treatment as well as psychological support...”

Traditional healers expressed their interest in learning about BC in order to learn more about the disease for the benefit of their patients. For example:

“...We, all traditional healers, do say that we need to attend those cancer trainings to learn new innovations, technologies, and interventions...”

Additionally, healers suggested that when education is provided in the wider community there is a wide space for the community members to attend health facility thereafter for further check-ups. For example:

“...Education and awareness should be provided to society. People should be open, and they should go for check-ups...”

A KI suggested that traditional healers should be educated on BC so that they can educate patients and refer cases that are beyond their ability to treat:

“...So that we may provide education even to those traditional healers because they do care for patients already; they will be better able to educate, to the extent of saying no this is where my ability ends, so I have to provide referrals...”

Providers also discussed infrastructure and services that might be helpful, such as health education for men and women that would promote breast screening and prompt men and women to seek medical attention if they notice any issues. These services would also teach about cancer, including its prevention and treatment, and the various parties involved in the process, as pointed out by a HCP:

“...If you should see any kind of problem on your breasts, please come quickly to the hospital and not to the traditional healers or anywhere else but the hospital... I would first begin with explaining the meaning of cancer. I usually tell them what cancer is, how it can be prevented and treated, and the people involved...”

Another male HCP added,

“...In the village areas, we teach people what cancer is, providing health education, and many people get this education. [They] must know what cancer is, how it occurs, what the signs and symptoms are, where they should go in case of the signs, what

type of investigations to expect, and what the cost is for the investigation, including the reports...”

KIs also suggested various ways to help raise BC awareness to facilitate early diagnosis, including increasing collaboration between THs and HCPs to prevent harmful practices, educating communities and involving religious institutions. For example:

“...It is true that breast cancer awareness in society is still very low, especially in the villages. The best and most effective way to educate them is through religious institutions. If they are well educated on breast cancer, they can be very good ambassadors, and they can greatly influence the community because they listen to them more...”

Similarly, one KI said,

“...We cannot really abandon the traditional healers in the health care system, but we can just work closely with them and ensure that they are playing their part well. They should also be the first to advise their cancer patients where to go to get the right treatment instead of staying with the patient for a long time, and they should know that there is nothing they can do to help them...”

Another KI added,

“...I think we need to collaborate with healers because as the Ministry of Health we can help their traditional treatment for clinical trials.... We can educate healers to become facilitators or educators to their cancer patients...”

4 Discussion

This is one of few studies that aimed to explore HCPs, THs' and KIs' perspectives on the late diagnosis of BC in northern Tanzania. Our thematic analysis revealed five main barriers to timely BC diagnosis and treatment: 1) HCPs, KIs and THs have limited knowledge and misconceptions of BC causes, signs and symptoms; 2) HCPs and THs blame each other for ineffective treatment and consequently delayed effective treatment; 3) patients experience stigma 4) treatments are difficult to access and expensive and 5) patients perceive barriers based on myths, misconceptions and spiritual beliefs. Moreover, recommendations for minimizing diagnostic delays were gathered from interviews with all stakeholders, such as raising BC awareness using local language, training THs on BC, and educating the general public on BC. By developing these suggestions, we aim to translate the identified barriers into concrete strategies that can mitigate delays in diagnosis and treatment. This section not only aligns with our overall goal of raising awareness about BC and improving BC care practices in Tanzania but also provides a practical road map for stakeholders, including policy makers, to implement changes that could ultimately enhance patients' outcomes.

4.1 Limited knowledge and misconceptions of BC

Lack of knowledge and awareness of BC was among the major themes in this study. However, it was the most important and earliest reason for late presentation to BC care in our study. The knowledge deficit among all THs, KIs and HCPs identified in this study is of particular concern. HCPs, unsurprisingly, offered accounts of BC that overall aligned more closely with biomedical models than those offered by THs, but striking

misconceptions and false beliefs were prevalent in both groups. Our findings are consistent with those of other studies [6, 17, 28], which reported little to no formal training in cancer for HCPs. A concerning issue is our finding that poor knowledge of risk factors is the primary cause of BC misdiagnosis. There is a need for improved BC awareness and comprehensive training programs in medical school to address these knowledge gaps. HCPs should understand the early symptoms and risk factors of BC to increase their ability to educate community members and promptly diagnose BC [29]. Overall, our findings revealed inadequate BC knowledge among all stakeholders, which must be urgently addressed. Addressing this existing knowledge gap will enable us to develop interventions aimed at reducing late diagnosis and promoting early detection.

4.2 Stigma

In all interviews, HCPs, KIs and THs noted that stigma negatively impacts early diagnosis and treatment. Patients fear being labelled as having cancer, being the subject of gossip, and hearing negative comments from both the public and their husbands. This finding is in line with those of previous studies that reported that perceived stigma results in non-disclosure of BC symptoms to avoid shame and lack of support from their husbands, in-laws and other family members [30–33] or to avoid being labelled sick or unable to work and care for their families [34, 35]. In addition, women harbor embarrassment about having a male doctor or TH examine their breasts [34].

Persistently poor outcomes of cancer among Tanzanian patients have created fear that it is an incurable disease, and people equate a cancer diagnosis with being given a death sentence. Breast cancer education emphasizing the curability of BC when detected early, explanations of the significant improvements in cancer care services, and their affordability to patients are crucial to encourage patients to seek timely evaluation. These suggestions may help the Tanzanian government develop cancer stigma reduction strategies. In addition, we found that participants believe BC to be associated with natural power, leading individuals to seek alternative interventions, such as prayers. That said, previous studies [36, 37] have found that incorporating spirituality-based content into church-based BC education could be a promising approach for women. This could be a promising BC awareness strategy to implement in Tanzania.

Based on our findings, sociocultural factors have implications for the diagnosis and management of BC, and there is a need to change how we think about BC. Rather than now where our patients think that BC is a disease of no cure, BC should be explained as a disease that affects women's lives, including their self-image and their relationships. When cancer is understood as a cultural phenomenon, this helps the community understand it more clearly [38].

4.3 Costs of treatment

Most patients cannot afford the costs associated with biomedical diagnostic and treatment services. The lack of affordable medical care [39] is a challenge in SSA, often limiting the health care options available for women, even if they decide to seek care. The costs associated with treatment by a TH are significantly lower than those of biomedical diagnostics and treatment; therefore, in some cases, THs are the only affordable choice for patients seeking care. Our findings align with a previous study [40] on the barriers to mental health treatment offered to Tanzanian citizens. In the prior study, HCPs

acknowledged critical shortfalls in providers, facilities and resources among services and multiple barriers that prevented patients from receiving care. Moreover, this earlier study reported that instead of seeking formal care, many individuals attempted to manage mental illness within their family and social networks or by seeking help from THs. Together, these findings support the importance of advocating for policy changes toward universal health coverage for cancer diagnostic and treatment services [41]. Policy changes that might reduce out-of-pocket patient costs and accelerate diagnosis include subsidies for diagnostic tests and formalized public and private arrangements to enable greater and more equitable access to the existing testing infrastructure available in the private sector. All of these suggested interventions must be coupled with advocacy and national and international measures to provide affordable diagnostic and treatment cancer services to Tanzanian citizens. The findings from this study highlight significant barriers to timely BC diagnosis and treatment, including economic disparities and the high costs associated with biomedical care. Many participants stated that the financial burden of diagnostic tests and treatments often forces patients to seek alternative, less effective care options, such as those provided by traditional healers.

4.4 Health system-related barriers

Challenges in health care workforce knowledge are compounded by the underdeveloped cancer care system within the Tanzanian health system. Both HCPs and THs expressed dissatisfaction with healthcare service delivery, with many THs expressing a clear mistrust of hospital treatment. These findings were reported in one of our defined themes. Our current findings align with previous studies that show that patients are dissatisfied with the care provided in health care facilities. For example, Kumar et al. (2019) reported that dissatisfaction with the quality of service, including negative attitudes of doctors and nurses, contributes to delayed BC diagnosis [42]. Bonsu and Ncama (2019) reported that possible misdiagnosis and mismanagement by public and private practitioners has led to mistrust of modern medicine and has led patients to seek alternative therapies [43]. Providing patients with accurate disease education, ensuring timely diagnosis and treatment, reducing long wait times, and communicating in patients' local language will foster trust between patients and HCPs [5, 28].

4.5 Mistrust among providers

In this study, we identified a significant finding regarding the dynamics of mistrust between HCPs and THs. Specifically, HCPs and THs often blame each other for providing ineffective care, which perpetuates a cycle of distrust. This blame manifests in various ways. For instance, HCPs frequently express frustration about THs' use of alternative treatments and believe that these options contribute to delayed diagnoses and worsen patient outcomes. Conversely, THs express skepticism about the capabilities of HCPs and allege that the biomedical care offered is insufficient and often leads to complications for patients.

This mutual blame not only highlights the breakdown in communication and collaboration among providers but also directly contributes to delays in seeking timely care for breast cancer. Patients caught in this discord may feel uncertain about whom to trust, prompting them to delay or avoid seeking care altogether. By shedding light on this critical aspect of provider relationships, the study underscores the urgent need for initiatives

aimed at building trust and fostering cooperation between HCPs and THs, thereby ensuring that patients receive comprehensive and effective care in a timely manner. Similar findings were reported in a study conducted in Tanzania that further highlighted the mistrust between HCPs and THs about mental health treatment. In this study, HCPs reportedly believed that THs promoted ineffective or fraudulent treatment for mental illness [44]. Given the mistrust between HCPs and THs, any collaboration-based intervention should allow providers to have a constructive dialogue about their work, clarify misunderstandings, identify mutual goals and consider opportunities for future collaborative interventions for the early detection of breast symptoms that may suggest BC.

4.6 Strengths and limitations

Our study has several strengths. We interviewed a sizeable and diverse group of participants with varying social standing, location, occupation and age, which helped us examine the barriers to late diagnosis from different perspectives and derive robust conclusions. To ensure a rigorous, thorough and ethical analysis of the participants' accounts, all the researchers kept notes in which they recorded their thoughts and feelings about the research process; this allowed the first author [EM] to identify any emergent biases and to adjust the research methods accordingly. All research decisions and their justification were documented in an analysis report (see Supplemental Material 2).

The transferability of our study was enhanced as we were able to describe the people who collected data, the process of data collection, the duration of each interview and how we conducted the analysis. Therefore, the study findings can be generalized to other similar settings in Tanzania and can have implication outside Tanzania.

The limitations is that the qualitative method with semi-structured interviews restricts the inclusion of many participants, which might affect the trustworthiness of the study compared to studies that use structured data collection. However, this study used various qualitative methods, such as IDIs, FGD and key informants, to minimize the risk. The researchers who conducted this study followed the interview guide and had no previous relation with the participants. We interviewed different participants with different demographic backgrounds, however, recall of past events with a foresight of experience and perceptions may unconsciously make the stories of these participants biased and inaccurate in explaining their experience and perspectives. Another limitation is the potential influence of interviewer-interviewee dynamics on participants' responses. For interviews conducted with non-medical personnel, participants may have felt hesitant to share openly due to perceived power imbalances in professional status. This dynamic could have limited disclosure of critical perspectives. Conversely, for interviewees who were also of the medical profession, shared training and background with the interviewer may have led to assumptions or common understanding, potentially limiting the depth or clarity of explanation provided during the interviews.

5 Conclusions

Our study highlights the complexities surrounding late BC diagnosis in northern Tanzania and identified breast cancer knowledge gaps, stigma among providers and patients, dissatisfaction with healthcare services, reliance on traditional healing, financial constraints, religious beliefs, and misconceptions about BC as significant barriers to timely diagnosis and treatment. These findings might be of relevant for cancer care screening

and earlier detection worldwide because similar challenges may exist in various health-care contexts. Crucial steps include developing culturally sensitive counselling resources, improving education for healthcare providers and traditional healers, and implementing national advocacy programs to make diagnosis and treatment more affordable. We advocate for further research to identify effective strategies to enhance BC education among traditional healers and healthcare providers, address stigma, and foster collaboration between these groups to streamline referral pathways.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12982-025-00920-z>.

Additional file1 (PDF 87 KB)

Additional file2 (PDF 694 KB)

Additional file3 (DOCX 35 KB)

Additional file4 (DOCX 36 KB)

Additional file5 (PDF 82 KB)

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Author contributions

E.F.M & B.T.M conceptualised and designed the study. E.F.M, P.C.M, B.C.K & V.F.S collected the data. E.F.M., L.G. & M.A. performed the formal analysis and contributed to the interpretation of the data, including coding. B.T.M. & L.G. supervised the study. E.F.M. investigation and project administration. E.K., B.T.M. & L.G. solicit funding to implement the study. Provide all resources to enable the study to be implemented. E.F.M. made the first draft. B.T.M, L.G, A.B, B.M, A.G, G.G.M, F.B.B, F.S, M.J, E.K, E.F.M, P.C.M, B.C.K, V.F.S, L.G & B.T.M write, review and edit the draft. All authors reviewed and approved the manuscript.

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Data availability

There are ethical constraints to sharing the data. We are unable to make these data available for public deposition because open data sharing was not specified in participants informed consent, nor in the approved ethical protocol for this study. We also have concerns about patients confidentiality in the sharing of detailed qualitative data, as the patients request can be made to National Institute for Medical Research (NIMR) IRB which can be reached by phone number + 255,222,121,400. For this study, please reference Protocol No. NIMR/HQ/R.8c/Vol.1/2342.

Declarations

Ethics approval and consent to participate

Participants signed informed consent for participation in the study.

Consent for publication

This study obtained ethical approvals from the KCMC University ethical review board (ref: 2425/Prop No. 1179, dated 27 June 2021), the National Review Board (ref: NIMR/HQ/R.8a/Vol./IX/3773, dated 29 July 2021) and the President's Office, Regional Administration and Local Government of Tanzania (PO-RALG-ref: AB.307/223/01 dated 27 November 2021). The study was carried out in accordance with guidelines listed in the ethics statements approved by the above ethics committees. Informed consent was obtained from all individual participants included in the study. This was done after each participant had been given full information about the study, and being informed of the freedom to withdraw at

any stage. In addition, the participants were assured of anonymity and confidentiality of their data/information, and no participant identifiable information was included in the manuscript.

Competing interests

The authors declare no competing interests.

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