BMC Women's Health

**RESEARCH** **Open Access**

# Factors Contributing to Late Breast Cancer Diagnosis: A Qualitative Study on the Patient's Perspective in Tanzania

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## Abstract

**Background** Breast cancer remains a significant public health issue worldwide, with late diagnosis leading to poorer outcomes. In Tanzania, many women are diagnosed with advanced stages of breast cancer. The aim of this study was to identify reasons for late presentations from the patient's perspective.

**Methods** Employing a qualitative study design, in-depth interviews were conducted with breast cancer patients. Purposeful sampling was used to recruit patients from inpatient and outpatient settings in the Cancer Care Center of the Kilimanjaro Christian Medical Centre. Eligible patients who were at least 18 years old, and with diagnosed breast cancer were invited for the interview immediately after their medical follow-up visit. Interview transcripts were analysed thematically.

**Results** Twenty patients (ten rural and ten urban) participated in the study. The average age was 54.05 years (SD = 9.46). Three women had stage 2, three had stage 3, and 14 had stage 4 breast cancer. Factors that were mentioned for late diagnosis of breast cancer were thematically grouped on three levels: the patient, community, and healthcare system. On the patient level, common reasons reported were a misunderstanding of breast cancer ($n = 19$, 95%), including lack of knowledge and awareness of breast cancer signs and symptoms, as well as the costs for transportation to the healthcare centre (10, 50%). On the community level, the reasons mentioned were experiencing stigma ($n = 19$, 95%) initially seeking care from traditional healers ($n = 18$, 90%), a burdensome spousal relationship ($n = 15$, 75%) and having faith in God ($n = 19$). On the health system level, patients ($n = 13$, 65%) expressed concerns regarding the high costs of cancer treatment, which limited their access to health care.

**Conclusion** Our findings show that, from the patient's perspective, the main reasons for delayed diagnosis of breast cancer can be grouped at the patient, the community, and the healthcare levels. Themes at the patient level are a lack of knowledge of breast cancer signs and symptoms and lack of awareness of having those symptoms. Community level themes were stigma, seeking initial care from traditional healers, and interacting with religious leaders, and themes related to healthcare included costs of cancer treatment, and negative attitudes of healthcare providers.

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**Keywords** Breast cancer, Late diagnosis, Perspectives, Tanzania

## 1. Introduction

Breast cancer (BC) is a major global health issue, causing millions of new diagnoses and deaths each year. BC is one of the most common cancer among women, with a significant number of deaths occurring in low and middle-income countries (LMICs) [1, 2]. While in high-income countries, mortality related to breast cancer is reported to decrease due to efforts made such as breast cancer awareness programs [3–6].

In Tanzania, breast cancer is the second most commonly diagnosed cancer and second leading cancer in both incidence and mortality among women after cervical cancer. In 2018, there were an estimated 3037 new cases and 1303 deaths in 2018, and it is expected to increase by more than 120% in both incidence and mortality by 2040 [7, 8]. The country has made an effort to combat this increase by adding a number of oncology facilities with digital diagnostic tools [9]. Despite these efforts, breast cancer is still commonly diagnosed at a late stage (III and IV), and the incidence is projected to increase by up to 82% by 2030 [3]. Unfortunately, access to treatment services in Tanzania is limited, which contributes to poor survival among the cancer patients [9].

It is well documented that a significant proportion of women in this region present to healthcare facilities with late stages of breast cancer and studies have shown that approximately 75% of women diagnosed with breast cancer in Sub-Saharan Africa present with stage 3 and stage 4 disease [1, 10–12]. Late stage presentation may, reflect patients' appraisal and decision processes based on experienced symptoms [13]., and is influenced by various patient related, socio-cultural and health system factors, such as misunderstanding of breast cancer, access to traditional medicine and long distance to the health care facility [14, 15]. The consequences of late-stage diagnosis include limited treatment options, poorer prognosis, and increased mortality rates. Lower educational attainment, increased travel time, lack of cancer knowledge and fear of cancer and cancer treatments were deemed to be associated factors [16–18].

To expedite breast cancer diagnosis, it is important to understand the reasons for late diagnosis of breast cancer among women in Tanzania. Previous studies conducted in Africa have mainly used quantitative approaches to examine specific barriers to early detection of breast cancer. For example, a cross-sectional study among 1129 women in Mwanza, Tanzania reported lack of knowledge on signs and symptoms of breast cancer, experiencing stigma, fear of losing a breast, fear of a poor diagnosis, and lack of knowledge of risk factors as the most frequent barriers to seeking care, which could lead to late diagnosis of breast cancer among women in the study setting [7, 10]. A qualitative study exploring factors contributing to delayed diagnostic evaluation among 12 women in Dar es Salaam, Tanzania found that delayed diagnostics, financial hardship, fear and stigma of cancer and the use of traditional medicine were reported [10, 18]. In addition, Mansouri et al. (2020) reviewed socio-economic status and factors contributing to the increase of BC in Tanzania. The study revealed that BC is the second most common malignant disease, with the majority of the patients being diagnosed at an advanced stage mainly due to either shortage of healthcare facilities, or not being able to afford health care services [19]. 'reasons for diagnostic delay from patients' own perspectives.'

However, a deeper understanding of factors that contribute to delayed diagnosis is important. Therefore, we aimed to understand the reasons for late diagnosis of breast cancer from the perspective of both rural and urban patients using a qualitative approach. The findings from this study will provide building blocks for evidence-based interventions to improve early diagnosis.

## 2. Methods

### 2.1 Study setting

The study was conducted at the Cancer Care Centre (CCC) of the Kilimanjaro Christian Medical Centre (KCMC), the only cancer centre in northern Tanzania. The CCC was established in 2016 and currently sees over 2000 patients annually. Breast cancer is the leading cancer among women in the CCC, with more than 400 women being followed up.

### 2.2 Study design

A qualitative description was chosen as the study design, as it is suitable for examining patients' experiences with medical issues; in particular by identifying themes in behavioural factors and underlying reasons for diagnostic delay from patients' own perspectives [20]. Although closely related to other approaches, qualitative description does not aim for a thick description as in ethnography, nor for theoretical development as in grounded theory, nor to interpret the meaning of experiences as in phenomenology. Rather, our study aimed to describe patterns in the data that may explain late-stage (stage III and IV) BC diagnosis and to formulate these in language close to the participants' own language. This allowed for the necessary broad and open exploration to gain insights into how breast cancer patients perceived and understood their illness, within the social and medical contexts which they navigate for their diagnosis and subsequent treatment that is pivotal for their survival and quality of life [20].

### 2.3 Recruitment of the study participants

A purposeful sampling method [21]. was used to recruit the participants. Participants were eligible if they were aged 18 years and above, with histologically confirmed breast cancer regardless of the stage, attending their medical follow-up, interested in the study with readiness to sign consent and to take part in the study. Breast cancer stage at diagnosis was not considered to be a selection criterion, because regardless of stage, patients have experiences and perspectives on the many patient, societal and health system factors that may cause late stage presentation and diagnosis. As we sought to capture the widest range of their perspectives, we did not want to exclude any patient.

Eligible patients were invited to participate in the study after their medical follow-up visit. We invited 20 participants, and all agreed to participate in the study, with none withdrawing consent [22, 23]. The sample size was determined by data saturation [22, 23]., however, we sought to recruit up to 20 participants, even if saturation was reached earlier to ensure a diverse range of perspectives and experiences across BC trajectories from our target population. Data saturation involved monitoring incoming data from interviews to determine a point at which little or no new information relevant to the study objectives was emerging. This was achieved through the interviewer summarizing key points raised by each participant following an interview. Key points were described and thus compiled across interviews, to support monitoring of interview data during the data collection period. During that process, key points were discussed with the research team to decide whether to proceed with the interviews or not. Although the extent of new information being identified was strongly reduced after the first thirteen interviews, we continued to the target of 20 patients to ensure maximum diversity within the sample.

Because participants were recruited immediately after their follow up visits, the sample may be biased toward women already engaged in care, which may limit the transferability of findings to women who do not reach or remain in the health system.

### 2.4 In-depth interviews

Two experienced researchers conducted 20 in-depth interviews with breast cancer patients (Urban = 10; rural = 10) from November 2020 to June 2021 at CCC in KCMC. After obtaining consent from participants, the in-depth interviews were conducted in a private space. The first author (EFM) conducted the interviews together with (PC) a researcher who was also taking notes during the interviews.

The semi-structured interview guide consisted of open-ended questions about knowledge of breast cancer and treatments and the factors that impacted on their presentation to a health facility. [See Appendix 1]. All the interviews were recorded using a digital audio recorder. Field notes were taken during the in-depth interviews, including observations and non-verbal cues from the participants. Interviews lasted between 60 and 90 min.

The first author, who conducted the interviews, is a nurse professionally. We acknowledge that this professional role may introduce power dynamics or influence participants' responses. To mitigate this, interviews were conducted in a private setting, participants were reminded that their care would not be affected by their participation or responses, and two researchers were involved during interviews to enhance transparency and reflexivity.

### 2.5 Data analysis

Within the qualitative approach, thematic analysis provided the guiding principles for data analysis, aiming to identify behaviours, experiences and perceptions that are relevant to diagnosis [24]. This analytic approach allows common and shared meanings to be synthesized into themes, defined as 'a patterned response or meaning' [25]. First, all the recorded interviews (in Kiswahili) were transcribed verbatim. Transcripts were crosschecked for errors by reading the transcripts together while audio-tape played. The transcripts were then translated into English and imported into NVivo software version 12 (QSR International, Melbourne, Australia) for coding. The six steps of thematic analysis as outlined by Braun and Clarke [26]. were applied to identify, analyse and report patterns within the data through an iterative coding process, that enables constant comparison of the interviews [24, 26]. We generated initial codes by reading and re-reading the transcripts. We grouped codes with similar semantic meaning, to create the themes. Themes were formed by staying close the actual quotes, thus using explicit or surface description from the transcripts, rather than through formulating new concepts [20, 26]. Two authors (EFM and MA) independently coded all transcripts, while authors LG and BCM guided the discussion of emerging themes, until consensus was reached. This iterative process allowed for the incorporation of new concepts and ensured robust development.

### 2.6 Quality assurance

To enhance the credibility and reliability of the study, data was collected from patients who were from different regions, involving patients from rural and urban areas to compare information gathered in different contexts.

Supervision of data collection, transcription and translation were done by first author (EM) and one translator and cross-checked by the authors BTM and EM who are fluent in both languages (Kiswahili and English). The study followed the COnsolidated criteria for REporting *Qualitative research* (COREQ) guideline for reporting qualitative research, including details of the research team, study methods, context of the study, findings, analysis and interpretations [27]. (See Supplementary file 1).

## 3. Results

Demographic details of the 20 female participants (10 rural and 10 urban) with confirmed breast cancer are summarized in Table 1. Their ages ranged from 40 to 59 years, average 56 years, most (70%) had primary or less education, most were unemployed (65%), and the majority (75%) were diagnosed with late-stage disease.

Our thematic analysis showed that common barriers reported by patients for advanced-stage breast cancer at the time of diagnosis appeared at three levels: the patient, the community, and the healthcare levels. The patient-level factors included a lack of knowledge of breast cancer signs and symptoms and lack of awareness of having those symptoms. Although rural patients appeared to be facing even higher barriers to access healthcare compared to urban patients, due to increased travelling distances, the thematic structure for both groups was the same. Second, the community level included stigma, seeking initial care from traditional healers, and interacting with religious leaders. Lastly, the health care level included costs of care and cancer treatment. A conceptual framework, outlining the major themes and sub-themes are summarized in Fig. 1.

**Table 1** Socio-demographic characteristics of the study participants

| CHARACTERISTICS | TOTAL *N* = 20 (100%) |
|---|---|
| Age* Mean [SD] | 54.05 [9.46] |
| Age (Maximum: Minimum) | (39–75) years |
| RELIGION | |
| Christian | 15 (75%) |
| Muslim | 5 (25%) |
| EDUCATIONAL LEVEL | |
| Never attended school | 3 (15%) |
| Primary school | 11 (55%) |
| Secondary school | 6 (30%) |
| EMPLOYMENT TYPE | |
| Employed | 7 (35%) |
| Unemployed | 13 (65%) |
| RELATIONSHIP STATUS | |
| Single | 3 (15%) |
| Married | 7 (35%) |
| Divorce | 5 (25%) |
| Widow | 5 (25%) |
| STAGE AT TIME OF DIAGNOSIS | |
| Stage I | 0 (0%) |
| Stage II | 3 (15%) |
| Stage III | 3 (15%) |
| Stage IV | 14 (70%) |

Note: Stages I and II are early invasive stages; Stage III is a locally advanced yet non-metastatic stage of breast cancer; Stage IV is metastatic breast cancer [28].

A narrative outline of sub-themes is presented below, with quotes accompanied by participants identifiers that can be found in Table 2.

### 3.1 Patient level factors

#### *3.1.1 Lack of knowledge related to breast cancer*

A major reason for delays in seeking health services was a lack of knowledge about cancer, such as misunderstanding signs and symptoms (19,95%).

> *"…The problem is that they did not hurt, if they did hurt every hour, I would rush to the hospital, I also think it was my negligence…" (Pt 02).*
> *"…I tried to check my breast and found that one breast had a distant swelling, something inside that was moving, and it wasn't in the other breast, so I was telling my fellow women, my friends, my breast has something inside, does yours have a similar thing?… they answered me saying women's breasts are like… I ignored it… but I was allowing the thing to continue growing…" (Pt 014).*

In addition, patients reported a lack of awareness of the following symptoms of breast cancer:

> *"…After staying for some time, that is when I started having pains in my breast …the same breast which is removed just started to hurt, and became hard, the swelling would come periodically for a few days, and then the breast would itch and then stop for about a week or two, last time I said, "no, this thing seems to go for six months, why should it continue like this?…" (Pt 018).*
> *"…I have no problem, the breast just grew swollen, I asked myself why it is getting fat in one place, I went to the hospital to check there was something hard. I told them over time, it grows like a boil… (they talk together) that it is because I was wearing these clothes…the bra… it appears like this…" (Pt 01).*

However, few participants (2,10%) reported cancer is misperceived as a transmitted disease. Despite reporting, that breast cancer is not contagious, participants felt they should take some precautions so that they would be able to protect other people. For example, one participant said,

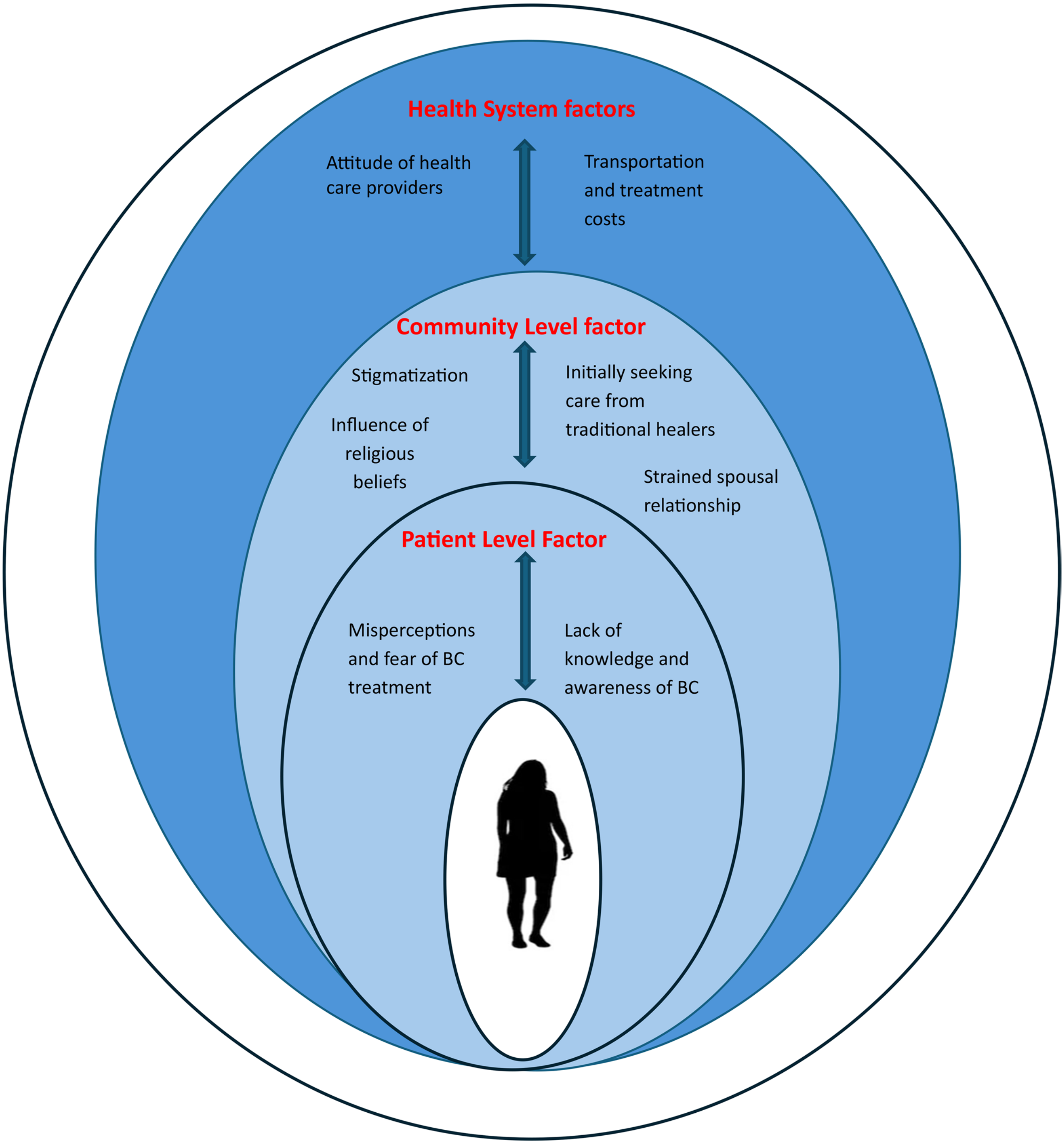

**Fig. 1** Factors related to diagnostic delayed of breast cancer among women in northern Tanzania according to Social Ecological system

> *"…They say cancer is not contagious but … just take precaution… things patients use as clothes do not mix too much with other people's clothes… I separate mine with those of my child…" (Pt 010).*

#### *3.1.2 Women's misperception and fear of breast cancer treatment*

Patients mentioned rumours prevailing in their communities, which caused panic and worry that cancer is an incurable disease, which induced great stress among patients.

> *"…Many say I was scared, everyone you talk to tells you it will be cut, I got scared maybe it's just the beginning of germs spreading quickly, maybe I will die quickly instead of living three years I will live for one year…" (Pt 05).*

**Table 2** Summary of participants identifiers to the quotes

| Participant number (PTNO) | Gender | Age | Setting | Diagnostic Stage |
|---|---|---|---|---|
| PT02 | F | 60 | Rural | 4 |
| PT014 | F | 48 | Rural | 4 |
| PT018 | F | 48 | Rural | 4 |
| PT01 | F | 40 | Rural | 3 |
| PT010 | F | 61 | Rural | 4 |
| PT05 | F | 67 | Rural | 4 |
| PT020 | F | 48 | Rural | 4 |
| PT03 | F | 57 | Rural | 4 |
| PT06 | F | 62 | Rural | 2 |
| PT019 | F | 47 | Rural | 3 |
| PT011 | F | 42 | Rural | 4 |
| PT017 | F | 48 | Rural | 4 |
| PT013 | F | 75 | Rural | 3 |
| PT07 | F | 58 | Rural | 2 |
| PT015 | F | 62 | Rural | 4 |
| PT09 | F | 51 | Urban | 2 |
| PT016 | F | 49 | Urban | 4 |
| PT04 | F | 59 | Rural | 4 |
| PT012 | F | 39 | Urban | 4 |
| PT08 | F | 64 | Rural | 4 |

> *"…why I should have my breast removed, if you have studied special education, they said there is no such thing as disability… developing it at old age is a psychological torture…" (Pt 020).*

In addition, participants thought radiation treatment would destroy their immunity rather than help. Some of the community members do not trust these new treatment methods, and many reported that they are afraid of these methods due to the side effects such as loss of hair and changes in skin and nails. When people hear about radiation or chemotherapy, they are afraid of its side effects and think that whoever receives radiation will die before she finishes the treatment. That makes breast cancer patients go to the healers for herbs after they have been prescribed to receive conventional medicine.

> *"…In my village, many people do not have good faith with radiation because many people who went to the hospital for mastectomy, have died. Once people heard that, they started to spread rumours… that is why people refuse this kind of treatment because of that…" (Pt 03).*
> *"…I was told not to trust XX hospital [Reginal Hospital], because they can cut it and later you realize that it is not a cancer, first go to XX [District Hospital] to confirm…" (Pt 06).*

## 3.2 Community level factors

### *3.2.1 Women with cancer experiencing stigma*

Almost all the participants (19,95%) experienced some kind of stigma before and after they were diagnosed with breast cancer. Misconceptions led to experiences of stigma, which included fear and worries about cancer, fear of being advised to go to the hospital, being treated as a dead person, lack of social support such as getting loans, being called a witch, devil, or strange person, and being ostracized by some people in community. Experienced stigma contributed to late diagnosis.

> *"…For me, my relatives reject me completely, as I am speaking, today's date is the date my family members refused me because of this problem. Each relative had a reason to refuse me and I know because they knew I would die…" (Pt 11).*
> *"…All my friends I had those days, everyone has run away from me because I am sick now…" (Pt 017).*
> *"…It is a fear. Also, women don't want to be known to have cancer. They fear that they may be isolated from their community… people think that, because you have cancer you may infect others, mmh… Cancer scares many people, it's not a joke. People who are coming to visit you are just coming to watch how you are doing, that is why I didn't like to tell anyone else…" (Pt 013).*

Participants went on to mention reasons why stigma occurs, which is uncertainty about how to live with someone who has undergone a mastectomy, resulting in fear and worries about the patient being 'bewitched'. Furthermore, cancer patients are regarded as dead persons, who can pass away at any time and have lost their ability to repay their debts since they will not be able to do any economic activity. As a result, patients lose their access to loans from the community.

### *3.2.2 Strained spousal relations*

Few patients (5,25%) shared experiences of their being supportive by ensuring their wives receive examination and other medical services while also helping to make treatment decisions. However, more than half (15,75%) of the participants had negative experiences with their husbands even before the diagnosis, which became worse after the diagnosis. According to these patients, their husband ran away after they discovered through the hospital that their wife suffered from breast cancer.

> *"…I was unable to work, that is when he left home. But now he has gone away completely, and I am alone. He knows it. He knows I am sick, but I am not close to him…" (Pt 07).*

> *"...They say women have a lot of challenges if you get a big problem, the man always runs away, when I got this, the man did not want it anymore, he came and asked the doctors about my diagnosis, and the love was completely gone...he gives harsh words that I can't cure cancer, I will die at any time, so he left me in a very difficult time...he took his child to boarding school..." (Pt 015).*

These women reported that their husbands felt like their wife had become a stranger, or even devil or witch, because they had never witnessed a woman who underwent mastectomy.

#### *3.2.3 Accessing initial care from traditional healers*

Most of the participants (18,90%) declared having contacted the traditional healer prior to receiving health care services. As a result, they started treatment from traditional healers until the condition became worse and the disease reached an advanced stage.

> *"...after taking the biopsy, it was tested, and I was told that I had cancer... I didn't follow up on the treatment: I was just drinking traditional medicines, and I even gained weight. A year later I developed a severe stomach-ache. I was brought for examination where it was discovered that even the breast was already destroyed..." (Pt 09).*
> *"...When I was diagnosed with cancer, I used natural remedies and recovered, later I wondered-how the breast started again, more intense than the beginning, coming here, they found it is at a bad stage...traditional healers are not honest. They are just looking for money... " (Pt 016).*

#### *3.2.4 Influence of religious beliefs*

Furthermore, the findings show that majority of the participants (18,90%) had faith in God, that they could get well, and that everything was God's will. They visit churches to talk to pastors who assure them that everything is God's wish, so they trust them. Some participants have been instructed to do things, which they believe will eliminate the disease, such as drinking anointing water.

> *"...Yes, I remember there was a pastor in Arusha because after being unconscious, I was taken to my children, and they would bring me to the pastor where he prays for me...another time, I called him on the phone... and said to him I feel pain... he told me take the water, I took the water, I opened and he asked to drink it, I drank the water and did not feel the pain anymore... just faith, now what will you do of course I put God first..." (Pt 04).*

> *"...I shared it with the priest before I cut the breast. I went to him, and he prayed for me. He took away my fear, he told me if it was God's work, I should go and follow the instructions that the doctor told me and I shouldn't afraid but trust God..." (Pt 01).*

### 3.3 Health system level factors

#### *3.3.1 Costs of cancer treatment*

More than half of the participants (13,65%) mentioned that the costs of cancer diagnosis and treatment are prohibitive for patients apart from those with health insurance, however even with health insurance, some costs were still prohibitive. Patients received financial support from their relatives such as children, husbands, sisters and occasionally from neighbours.

> *"...What I needed to do was look for 500,000 Shillings so that they could perform surgery where they would take a biopsy, and I thought that I was spending too much money on my problem. The money for payment was really a big challenge. We were told that there was no medicine, and they called the pharmacy to ask if they had that medicine and how much it was going to cost. They told us that they had the medicine and that it cost 380,000 shillings. I didn't have the money, but my relatives said that God was faithful and that he was going to provide. We went home and started informing our relatives..." (Pt 012).*

However, despite financial support, it was still difficult for few participants to pay for cancer the diagnosis and treatment, and this was reported to be with traditional healers as well.

> *"...the medicine cost me one thousand and fifty hundred Tanzanian shillings. The traditional healer initially wants a patient to pay one hundred thousand Tanzanian shillings, then the rest of the money to be paid once a patient completes the dose. I paid only a hundred thousand, but when I used it there was no good progress. I stopped taking it..." (Pt 08).*

However, patients who visited healthcare facilities were already concerned about the high charges for testing and diagnosis, and this often influenced their decision to go back home and try other remedies that seemed less expensive.

#### *3.3.2 Attitude of health care providers*

Some participants were discouraged by health providers whenever they attended health facilities for checkups for example, "*the service provider would look at the client* *and say, 'why do you want to check your health, you don't have cancer, just go back home'"*(Pt 06). Some reported back with advanced stage of the disease.

> *"...I went to the hospital for first time for a check-up, I got there I told a doctor, and he was like testing you if you have any problem..., he rejected me, claiming that they test people who are sick, so if doctors themselves do that, I wanted to be tested...today, I have a big problem,: I was discouraged by the professional doctor..." (Pt 06).*

#### *3.3.3 Challenges with transportation costs*

Finally, transport costs were categorized as a health-system factor because they reflect structural and geographic barriers to accessing oncology services, even though their impact is experienced at the individual patient level. The cost of health care treatment was further increased due to transportation costs since most of the participants lived far from the facility. The treatment itself was much higher compared to their living standards.

> **"...***Yes, Life is hard to get money to come to the hospital, I suffer, a file is five thousand shillings, the fare and then again to look for medicine is a challenge, that is why at times I beg, using it for ten years will I survive? Still, seven years to come, where will I find the money...***"** *(Pt 019).*

## 4. Discussion

Our study aimed to understand the perspectives of both rural and urban patients on late-stage diagnosis of breast cancer using a qualitative approach to highlight opportunities for future research and intervention. Late-stage diagnosis results from the delay between the time the patient first notices symptoms of breast cancer and the time she first attends the health care facility [29]. This study identified seven main barriers, at three levels, for the late diagnosis of breast cancer from the perspectives of both rural and urban patients. Patient- level barriers include lack of knowledge of breast cancer and misperceptions regarding breast cancer treatment; community-level barriers include experiencing stigma, interacting with traditional healers and having faith in God, while costs of cancer treatment and transportation were health care system-level barriers. To our knowledge, the current study is one of the first to use a qualitative approach to investigate the reasons for late diagnosis from the perspective of a diverse sample of breast cancer patients.

Our study identified a lack of knowledge about signs and symptoms, as well as misconceptions about breast cancer as major reasons for the delay in seeking health care services. As a result, women are less likely to perceive the disease as serious. Our findings are consistent with findings from studies done in Malawi, Tanzania and Ethiopia, which also identified a lack of knowledge as a reasons for delays [7, 10, 14, 30–32]. This calls for more community awareness of breast cancer signs and symptoms, but also of the care available, to motivate them to seek healthcare services at earlier stages.

Stigma from self and others was reported by almost all the participants in this study. Stigma was associated with negative perceptions about mastectomy, e.g., that the wound will not heal, and the patient will die. Our study findings are mirrored by previous studies. For example, a study done in Ghana found that community perceptions of women are defined by their breasts [33]. Another study conducted in South Africa indicated that fear related to treatment, especially radiation, as well as loss of hair or breasts, was a great issue among breast cancer patients [34]. In turn, stigma and resulting fear may lead not to disclosing the symptoms, not even to close family members, hence, delays in seeking care while providing time for disease progression. Instead of attending healthcare facilities, patients decide to consult traditional healers, which leads to delayed diagnosis. Furthermore, in a systematic review and meta-analysis on delayed presentation of breast cancer patients and contributing factors quantifies the effects of factors such as rural residence, lower education, using traditional healers, long distances and absence of pain in delaying presentation [35]. These findings provides strong quantitative backing to our present study calls for policy intervention. Therefore, further research on breast cancer stigma is needed to provide insights into how to reduce it.

Lack of support from the husband was a significant theme reported in this study. More than half of the participants in this study endured relational hardships, such as separation, after having been diagnosed with breast cancer. Similar findings was reported by Abraham, (2025), which shows that, husband support (or lack thereof) is empirically observed to delay presentation [36]. Moreover, the male-controlled social structure of the society provides lesser economic opportunities to women, rendering them dependent on their male partners. Thus, poor economic conditions and financial dependence pose an important barrier to breast cancer treatment [37, 38]. Previous studies also reported partner abandonment and lack of partner support as negative consequences of breast cancer diagnosis and treatment, as well as barriers to accessing health care [39–41]. However, in another study, husbands expressed that their wives' breast cancer positively affected their relationship and made them feel closer to their wives, although they reported feeling shy looking at their wives bodies after the surgery [42]. Awareness creation, early involvement and counselling of patients, husbands and families may also support reducing fear and stigma and increasing support to the affected. To change norms around breast cancer and to support future patients, educational interventions should ideally target al.l males in a community, instead of only husbands of cancer patients.

Furthermore, the use of traditional medicine was common, and a primary reason for late-stage diagnosis in this study. We found that to some participants seeking medical care was the second option only after the failure of traditional medicine. This is in line with a study conducted in Uganda, where it was found that more than half of the participants reported the use of traditional medicine to treat cancer [43]. However, the majority of those who opted for traditional medicine never disclosed this when attending healthcare facilities, due to lack of inquiry by the healthcare professionals and fear of disapproval and/or rebuke [43]. Similarly, a study done in Ethiopia identified the belief in traditional medicine as a major barrier to early diagnosis of breast cancer [14]. Strikingly, another study from Ethiopia found that 52% of breast cancer patients reported traditional medicine as their first choice once they suspect a problem. Reasons for visiting traditional healers mentioned by these participants were dissatisfaction with biomedical medicine and its costs [44]. A better understanding of the role of traditional healers in communities and targeted interventions to increase their knowledge and awareness can enable them to recognize the signs and symptoms of breast cancer at an early stage. This allows for faster referral to healthcare facilities.

In this present study, financial constraint was a barrier that repeatedly emerged from the interviews. Financial challenges can affect women's decisions to seek care from the healthcare facilities, including seeking timely breast cancer screening and treatment. These findings are also reported in previous studies, which showed financial constraints [10, 18, 45–49]. and access to healthcare providers [50–58]. determined healthcare utilization of breast cancer patients. In Tanzania, breast cancer screening is free of charge; however, treatment facilities are scarce, resulting in large distances to healthcare facilities, and thus high travel costs. Similar findings was reported by [35, 59]. In addition, costs for the treatment and tests often require out-of-pocket payments even with health insurance.

Taken together, our findings demonstrate that delays in breast cancer diagnosis arise not from isolated barriers but from dynamic interactions across patient, community, and health-system levels. For example, stigma surrounding mastectomy and cancer treatment can intensify fear, which in turn prompts concealment of early symptoms and encourages women to seek help first from traditional healers. Similarly, spousal abandonment or strained partner relationships exacerbate women's financial insecurity, limiting their ability to afford travel to distant treatment centers an effect amplified by structural gaps in service availability. These interconnected pathways create reinforcing feedback loops that compound delays, as shown in our conceptual framework (Fig. 1). Understanding these cross-level dynamics is essential for designing interventions that address not only individual knowledge gaps but also the community norms and structural barriers that shape women's healthcare-seeking behavior.

Collectively, recent studies confirm that late breast cancer diagnosis in Tanzania and across East Africa is shaped by multi-level barriers, including limited awareness, stigma, financial constraints, and health system challenges [35, 36, 59, 60]. While some research has concentrated on particular populations, such as rural women [59]or the role of spousal support[36], and others have addressed regional patterns [35], our study contributes by integrating both rural and urban patient perspectives. By situating barriers at the individual, community, and system levels within a single analytical framework, this study offers a comprehensive, patient-centred perspective. Such an approach generates actionable insights that can inform interventions designed to be both culturally sensitive and context-specific.

### Recommendation for the Healthcare system

Decentralizing cancer services to regional and district hospitals, supported by diagnostic tools, oncology staff, and referral systems, can reduce access barriers and ease the burden on specialized centres. When combined with financial measures such as transport reimbursement or cost exemptions these strategies can facilitate earlier detection, improve treatment outcomes, and ultimately reduce breast cancer mortality.

To strengthen the real-world applicability of these recommendations, opportunities exist to integrate breast cancer awareness, early detection, and referral into existing service delivery platforms in Tanzania. Breast health education and clinical breast examinations can be incorporated into HIV care clinics and RMNCH services, which already serve large numbers of women. Community health workers who are well established in Tanzania can play a central role in household-level education, symptom recognition, and referral.

In addition, traditional healers and religious leaders, who remain trusted first-contact providers for many women, could be engaged as referral partners through targeted training. These strategies align with Tanzania's decentralization agenda, which aims to expand diagnostic and treatment capacity at regional and district levels, thereby reducing delays and facilitating earlier access to cancer care.

### Strengths and limitations

Our study has several strengths and limitations. To our knowledge, this is the first study conducted in Tanzania to explore patients' perspectives on late breast cancer diagnosis. The interviewed sample was diverse in terms of its demographic background (i.e. educational level, age, and from both rural and urban locations). This enabled acquiring a wide range of experiences and perspectives, increasing the validity of the presented thematic structure. This was further strengthened as the number of interviews well exceeded the number at which saturation became apparent.

However, we felt that participants were open about their personal experiences; breast cancer is a sensitive topic because it is life threatening and heavily stigmatized. This may have stood in the way of full disclosure by participants. A related point is that participants' responses may have been biased by what they believe are socially desirable answers. This may be because of a power gap, as the author is also a nurse, as well as a researcher, which inadvertently may have led participants to perceive her as a an authority figure.

Finally, the identified barriers could have been related to late stages as identified in the Anderson Model of Total Patient Delay [13]. This may have resulted in additional or more specific insights into patient factors related to diagnostic delay. However, this model is mostly recommended for medically oriented studies that examine the diagnosis and any delay itself. In contrast, the present study aimed to explore reasons for the delay from the patient perspective, by focusing on the psychological and social factors as experienced by patients throughout their diagnostic and treatment trajectories. As shown, these factors pervasively guide decision making and are thus not necessarily meaningfully relatable to the chronological Anderson Model".

### Recommendation for Policy and Practice

The findings of this study highlight several priority areas for intervention. Reducing stigma should be a central component of national cancer strategies, achieved through community-based awareness campaigns that engage breast cancer survivors, religious leaders, and local authorities to normalize disclosure and encourage timely health-seeking. Equally important is the training of front line healthcare providers to enhance their capacity for early detection, accurate diagnosis, and effective treatment of breast cancer. Strengthening the involvement of families, particularly male partners, through counseling and education may reduce abandonment, foster social support, and increase women's willingness to seek care. Integrating breast cancer education and screening into existing health platforms, including HIV clinics and reproductive health services, presents an efficient approach to broaden reach and capitalize on existing infrastructure. Collaboration with traditional healers offers another important avenue, given their trusted role in many communities; providing them with training on breast health and referral pathways could facilitate earlier entry into the healthcare system. Finally, addressing financial and structural barriers through decentralization of diagnostic and treatment services to regional, district, and primary health centers, coupled with financial protection measures such as transport reimbursement or exemptions from cancer-related costs, is essential. Together, these strategies hold strong potential to promote early detection, improve treatment outcomes, and reduce breast cancer mortality in Tanzania.

## 5. Conclusion

Our findings show that, from the patient's perspective, the main reasons for delayed diagnosis of breast cancer can be grouped at the patient, the community, and the healthcare levels. Themes at the patient level are a lack of knowledge of breast cancer signs and symptoms and lack of awareness of having those symptoms. Community level themes were stigma, seeking initial care from traditional healers, and interacting with religious leaders, and themes related to healthcare included costs of cancer treatment, and negative attitudes of healthcare providers.

These findings can inform tailored culturally sensitive interventions such as public health campaigns, increase breast health education to the community members to alleviate the misconceptions as well as fill the knowledge gap, promote early detection, improve treatment outcomes, and reduce breast cancer mortality in this region. Furthermore, system- level changes such as exemption to financial challenges to patients and empowering both health centers and District care facilities with cancer resources might enable navigation pathways to facilitate timely referrals to specialized hospitals for early diagnosis and treatment. There is a need to conduct further study to investigate the knowledge, attitude and practice among traditional healers in order to address this knowledge gap and reduce mortality related to advanced-stage diagnoses seen at health facilities. Ultimately, Interventions at all levels, including policy, provider, individual and community levels, are needed to address these observed pathway challenges.

#### Abbreviations

| | |
|---|---|
| BC | Breast cancer |
| CCC | Cancer care centre |
| COREQ | COnsolidated criteria for reporting qualitative research |
| HIV | Human immunodeficiency virus |
| KCMC | Kilimanjaro christian medical centre |
| LMICs | Low and middle income countries |
| NVivo | NVivo Qualitative data analysis software |
| QSR | QSR International (Developer of NVivo software) |
| SD | Standard deviation |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12905-025-04213-0.

Supplementary material 1.

Supplementary material 2.

**Acknowledgements**

We thank all the study participants for accepting to be part of this study and for the information, they shared as part of the data collection. We also express our gratitude to the healthcare providers for their support during data collection. The Regional Administrative Secretary (RAS) and Kilimanjaro Christian Medical Centre are thanked for granting permission to conduct this study. I am especially indebted to Dr. Agnes C. Msoka, Dr. Ayesiga Herman from Kilimanjaro Christian Medical Centre, KCMC University. Emma McIntosh, Professor of Health Economics, School of Health & Wellbeing, College of Medical, Veterinary and Life Sciences. Christopher Bunn, School of Social and Political Sciences, University of Glasgow, UK and Sally Wyke, Interdisciplinary Professor of Health and Well-being from School of Social and Political, School of Health and Well-being College of Social Science, University of Glasgow, UK who have been supportive of my career goals, they shown me, by their examples, what a good scientist and a person should be.

### Authors' contributions

EM: Conceptualization, Methodology, Data curation, Analysis and interpretation of data, Writing the original and final manuscript drafts, writing and editing, Funding Acquisition and Project administration. MA: Formal Analysis, Validation, Writing-Review & Editing. FS: Writing-Review & Editing. PC: Data curation, Analysis and interpretation of data. AK: Data curation, Analysis and interpretation of data. BK: Data collection and data curation. VS: Data curation, Analysis and interpretation of data. FB: Writing-Review & Editing. OH: Writing-Review & Editing. GM: Writing-Review & Editing. BCM: Data analysis, Validation, Supervision, Writing-Review & Editing. CB Writing-Review & Editing. MJ: Writing-Review & Editing. EK: Writing-Review & Editing. LG: Data analysis and interpretation of data, Writing-Review & Editing, Visualization, Supervision, and Funding Acquisition. BTM: Writing-Review & Editing, Visualization, Supervision, Funding Acquisition. The final manuscript was approved by all authors.

**Funding**

This project was conducted with funds from the University of Alabama at Birmingham and Kilimanjaro Clinical Research Institute administration funding qualitative data analysis. Also, this work was supported through NORA Consortium, funded by the German Federal Ministry of Research, Technology and Space 01KA2220and REACCT-CAN funded by Science for Africa Foundation to the Developing Excellence in Leadership, Training and Science in Africa (DELTAS Africa) program [De-22-008] with support from Welcome Trust and the UK Foreign, Commonwealth & Development Office and is part of the EDCPT2 programme supported by the European Union and Global Health Working Group, Martin Luther-University Halle-Wittenberg (Grant number [81295996]. The authors are responsible for the study findings and reporting. The funders have no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. The authors are responsible for the study.

### Data availability

Anonymized data are available on reasonable request by writing the corresponding author.

## Declarations

### Ethical approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations. Throughout the study, the ethical principles of the Declaration of Helsinki were followed. Ethical approval was granted from the local ethical reviewed board, College Research Ethics and Review Committee (CRERC) (ref: 2425), the National Institute of Medical Research (NIMR) (ref: NIMR/HQ/R.8a/Vol./IX/3733), and from the President's Office, Regional Administration and Local Government of Tanzania (PO-RALG) (ref: AB.307/223/01). Written informed consent was obtained from participants after reading a participant information sheet to them.

### Consent for publication

Not applicable under this section.

### Competing interests

The authors declare no competing interests.

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Received: 25 May 2025 / Accepted: 3 December 2025

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## Publisher's Note