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## A framework for improving early detection of breast cancer in sub-Saharan Africa: A qualitative study of help-seeking behaviors among Malawian women



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#### ABSTRACT

Objective: Many women in Africa are diagnosed with advanced breast cancer. We explored Malawian breast cancer patients' perspectives about their diagnosis and ability to access care to identify help-seeking behaviors and to describe factors influencing delay.

*Methods*: We purposively sampled 20 Malawian breast cancer patients to conduct in-depth interviews. Transcripts were double coded to identify major themes of breast cancer help-seeking behaviors and what delayed or facilitated access to care.

Results: We outlined a breast cancer help-seeking pathway describing decisions, behaviors, and interactions from symptom presentation to receipt of cancer care. Patients were largely unaware of breast cancer and did not immediately notice or interpret symptoms. As symptoms progressed, women inferred illness and sought help from social networks, traditional remedies, and medical care. Economic hardship, distance to the facility, provider knowledge, health system factors, and social norms often delayed reaching the facility, referrals, diagnosis, and receipt of care.

*Conclusions:* Social-contextual factors at the individual, interpersonal, health system, and societal levels delay decisions, behaviors, and access to breast cancer detection and appropriate care.

Practice implications: A comprehensive approach to improving breast cancer early detection must address public awareness and misconceptions, provider knowledge and communication, and cancer care delivery.

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#### 1. Introduction

Breast cancer is the most common cancer in Africa (134,000 cases in 2012), and incidence is expected to continue to increase. It is also the leading cause of cancer death; the mortality to incidence ratio in Africa is 47%, compared to 19% in the US [1]. High mortality rates are likely due to low awareness, many women being diagnosed with advanced disease, and lack of screening and

diagnostic services [1–3], all of which underscore the need to explore factors affecting early detection and treatment initiation.

A woman's decisions and ability to access cancer care may be influenced by individual psychosocial factors and lived experiences as well as broader social-contextual influences and interactions with her environment [4,5]. Systematic reviews of quantitative and qualitative breast cancer studies found that delays greater than three months affect breast cancer survival [6–9]. Common risk factors for delay include low socioeconomic position (SEP), lack of cancer knowledge, embarrassment of being examined, and distance to the health facility [10,11]. However, few studies from Africa, where health resources are scarce, cancer awareness is low, and screening is uncommon, have been conducted or included in such reviews. Previous qualitative studies are largely descriptive, and few developed conceptual models to understand the complex

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factors influencing delayed and early detection [10,12,13]. Additionally, few delay models have explored the influence of alternative treatments and traditional medicine, which are commonly used among cancer patients across Africa [14].

Therefore, the objective of this study was to explore how Malawian women accessed breast cancer care and what influenced their decisions and ability to seek help. This paper proposes a framework, grounded in findings from in-depth interviews, to understand delay and improve early detection and treatment initiation in sub-Saharan Africa (SSA). We describe potential breakdowns at specific stages, transitions between stages, and how different factors can cause delays along the breast cancer help-seeking pathway.

#### 2. Methods

#### 2.1. Study setting

The study was conducted in Lilongwe, Malawi, as part of a larger project investigating breast cancer knowledge and preferences. Malawi is a small, densely populated country in SSA. Over 80% of the population lives in rural areas and relies on subsistence farming [15]. The public health system provides free basic services through local health centers, small district hospitals, and referral tertiary care hospitals. Cancer is an increasingly important problem for the resource-limited health system [16–18].

#### 2.2. Study design

We conducted in-depth interviews because they are well-suited for exploring how people give meaning to their lived experiences [19] and can provide insight into how people interpret and act on symptoms while considering the local environment and cultural context. We recruited breast cancer patients from Kamuzu Central Hospital, one of two teaching hospitals where breast cancer treatment is available. Local fieldworkers, trained in social science research, and oncology clinic staff identified patients  $\geq$  18 years of age with confirmed pathologic diagnosis of breast cancer. We used purposive sampling to incorporate a range of perspectives including differences in age, residence, and educational attainment; we recruited women with different backgrounds to ensure representation across groups and until we reached saturation. Eligible patients provided written and verbal informed consent. The authors' institutional review board and the Malawi National Health Services Research Committee approved this study.

#### 2.3. Data collection

Interviews were conducted in a private room between April and August 2014. The fieldworkers and principal investigator met regularly to discuss the responses and revise the semi-structured interview guide as additional topics emerged. Broad topics in the interview guide included help-seeking behaviors, breast cancer knowledge, symptom experiences, and diagnosis and treatment barriers. Interviews lasted 48 minutes on average.

All interviews were conducted in Chichewa, recorded, transcribed verbatim, and translated into English. Translation consultations occurred regularly to review problematic words. Multiple pages of four transcripts were back translated to ensure the meanings of the interviews were not lost.

#### 2.4. Data analysis

Transcripts were analyzed in Atlas.ti 7 (Atlas.ti Scientific Software Development, Berlin, Germany). We used an inductive coding approach initially and then grouped codes to create a

codebook based on the social contextual model [4] and the preliminary interpretation of participants' responses. Through an iterative approach, two readers (REK and ARM) independently coded transcripts, discussed divergent applications, revised definitions, and added new codes until consensus was reached. We identified overarching themes and compared code frequencies and co-occurrence patterns across groups. We also used Strauss and Corbin's paradigm approach to organize and conceptualize the conditions, actions/interactions, and consequences within transcripts [19], diagramming various trajectories women narrated to represent help-seeking patterns.

#### 3. Results

#### 3.1. Sample characteristics

We recruited 20 patients with varied levels of education, employment status, age, and residence (Table 1). Women were at different phases of cancer care, including recently diagnosed, receiving neoadjuvant chemotherapy, receiving adjuvant chemotherapy, under surveillance care, and receiving palliative care for metastatic disease. The median age was 47 years. All women were symptomatic when they were diagnosed. Their experiences illustrated a complex set of factors that influenced help-seeking behaviors and led to delays between symptom onset, diagnosis, and treatment initiation ranging from a few weeks to a few years.

#### 3.2. The breast cancer help-seeking pathway

The pathway comprises six stages that emerged from the interviews (Fig. 1). It is displayed with sequential stages, but represents a complex decision-making process with different trajectories such as moving quickly, getting stuck, skipping steps, or looping back to earlier stages. This patient's description exemplifies the process:

**Table 1** Characteristics of Malawian breast cancer patients.

	N (%)
Age group	
25-40 years	9 (45)
41-55 years	4 (20)
56+ years	7 (35)
Marital status	
Married	15 (75)
Single/divorced	2 (10)
Widowed	3 (15)
Religion	
Christian	18 (90)
Muslim	2 (10)
Residence	
Lilongwe	12 (60)
Other district	8 (40)
Education	
No formal schooling	5 (25)
Some primary school	8 (40)
Some secondary school	7 (35)
Economic position	
Electricity in house	5 (25)
Regular source of income	8 (40)
Roof type	
Iron sheet roof	11 (55)
Grass thatched roof	9 (45)

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