

Breast Cancer Knowledge, Behaviors, and Preferences in Malawi: Implications for Early Detection Interventions From a Discrete Choice Experiment

abstract

Purpose Breast cancer is the most common female cancer in Africa and leading cause of death resulting from cancer; however, many countries lack early detection services. In Malawi, women are frequently diagnosed with large tumors after long symptomatic periods. Little is known about local cancer knowledge.

Methods We administered a cross-sectional survey with a discrete choice experiment to a random sample in urban and rural areas of Lilongwe district. Bivariable and multivariable analyses determined factors associated with knowledge. Preference utilities for early detection interventions were estimated using a hierarchical Bayesian model in Sawtooth software.

Results Of 213 women recruited, fewer than half were aware of breast cancer. In multivariable analysis, electricity at home and knowing someone with cancer increased the odds of awareness. Women were more knowledgeable about symptoms than treatment or risk factors; more than 60% erroneously believed local misconceptions. Seventeen percent were aware of breast self-examination, and 20% were aware of clinical breast examination (CBE); few reported either behavior. Common barriers included not knowing where to access CBE and transportation difficulties. Discrete choice experiment results indicated the detection strategy (breast health awareness, CBE, or both) was the most important attribute of an intervention, followed by the encounter setting and travel time.

Conclusion Addressing misconceptions in health messages and engaging survivors to promote early detection may help improve breast cancer knowledge in Malawi. Program designs accounting for women's preferences should provide breast health education and CBEs in convenient settings to address transportation barriers, particularly for women with low socioeconomic position.

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INTRODUCTION

Breast cancer is the most common cancer in Africa and is also the leading cause of death resulting from cancer among female patients.¹ High mortality rates are likely a result of low awareness, large proportions of advanced diagnoses, and a scarcity of screening, diagnostic, or treatment services.²⁻⁶ Knowledge of the disease and available detection strategies is essential to increase early diagnosis and improve outcomes.

Studies from African countries have shown that cultural and religious beliefs, competing health needs, and low socioeconomic position (SEP) are associated with low breast cancer knowledge and poor help-seeking behaviors.^{7,8} However, previous studies investigated mammography knowledge

and behaviors^{9,10} or surveyed health workers or medical students¹¹⁻¹³; few studies have assessed knowledge in the general population.¹⁴⁻¹⁷ Country-specific data are needed because of differences in health system resources, cultural nuances, and social contextual factors.

In Malawi, one of the most resource-limited countries in the world, patients with breast cancer are commonly diagnosed at young ages with large tumors after long symptom duration.^{18,19} Although national health guidelines recommend promoting breast health awareness, including breast self-examination (BSE) and clinical breast examination (CBE), these services are not widely available.²⁰ International recommendations support these resource-appropriate early detection

and diagnosis strategies because of the current lack of resources required for mammography.^{2,3} To date, no studies have assessed Malawian women's breast cancer knowledge, which is imperative to develop locally appropriate public health interventions. The objective of this study was to investigate knowledge, behaviors, and preferences about breast cancer and early detection among Malawian women.

METHODS

Study Setting

This cross-sectional study was conducted in Lilongwe district in central Malawi. The district includes the capital city Lilongwe, one of four major urban areas in the country, many transitioning periurban residential areas, and rural traditional authority areas.²¹

The public health system provides free basic health care through local health centers, district hospitals, and four tertiary care hospitals. Two tertiary care hospitals offer chemotherapy for patients with breast cancer; no radiotherapy is available in Malawi. There is no functioning mammography equipment in the public system; however, mammography is available in the private sector for approximately US\$125.

Study Design

We considered Lilongwe city and the rural traditional authority areas separately and sampled them in proportion to the female population. We randomly selected geographic coordinates within residential areas using ZMaps (Zonums software; <http://zonums.com>). Fieldworkers used handheld Garmin GPS devices (Olathe, KS) to locate the coordinates and conducted three interviews around each coordinate (Data Supplement provides recruitment procedures and eligibility details). The study was approved by University of North Carolina Institutional Review Board and the Malawi National Health Service Research Committee.

Data Collection

Data were collected in the local language (Chichewa) via interviewer-administered surveys from July to August 2014. Fieldworkers entered responses into Open Data Kit Collect (Open Data Kit software; <https://opendatakit.org>) on tablets, and data were uploaded daily.

Measures

The survey included questions on knowledge, beliefs, and behaviors regarding breast cancer, BSE, CBE, and demographic characteristics.

Questions were conceptually derived from the Health Belief Model, which posits that multiple factors influence the adoption of health behaviors, including perceived threat of a health condition, perceived benefits and barriers, cues to action, and self-efficacy.^{22,23} Traditional instruments measuring Health Belief Model variables, such as Champion's breast cancer beliefs measures,²⁴⁻²⁶ do not assess CBE beliefs and may not be valid in an African context. Therefore, we adapted scales to match locally available strategies (Data Supplement).^{25,26} Fatalism measures derived from Powe's scale assessed beliefs about the inevitability of death associated with a cancer diagnosis.²⁷ We used "yes," "no," or "don't know" responses because of difficulties in translating meaningful Likert-scale responses. Knowledge scores were calculated by summing correct responses for signs, risk factors, and treatment options.

Discrete Choice Experiment

A discrete choice experiment (DCE) is used to elicit preferences for health services.^{28,29} This approach is based on the assumption that a health service can be broken down into separate attributes, and the total utility gained from using that service is a function of the individual utilities of the attributes.³⁰ Respondents are given hypothetical scenarios and forced to choose one preferred option.³¹ Respondents should choose the scenario producing the highest utility.³² Estimation models calculate utilities for each attribute level and determine the relative importance of attributes.

We previously described the development of the DCE, where we followed the International Society of Pharmacoeconomics and Outcomes Research guidelines to determine optimal design.^{32,33} The DCE attributes included travel time (< 1, 1 to 2, or > 2 hours by foot), intervention encounter or setting (health talk in facility waiting area, community health gathering, cervical cancer screening, family planning [FP] clinic, or well-child visit clinic), health worker (physician or health surveillance assistant), health worker sex, and early detection strategy (breast health awareness, CBE, or both).

We used Sawtooth software (version 8; Sequim, WA) to create an efficient and balanced fractional factorial design. Cognitive testing suggested that 16 choice cards were burdensome, so we presented nine cards with two scenario descriptions and images of the attribute levels on each. A multiple-choice design also complicated comprehension, so we used a binary choice format.³³

Statistical Analyses

Sociodemographic characteristics, knowledge, beliefs, and behavior responses were summarized descriptively using STATA software (version 13; STATA, College Station, TX). We used multivariable logistic regression to identify associations with knowledge and assessed covariates one by one. Collinearity was evaluated with Pearson's correlation coefficient; personal water tap was excluded because of significant correlation with electricity.

The DCE results were analyzed using the hierarchical Bayesian module for choice-based conjoint analysis in Sawtooth software.³⁴ A multinomial logit model estimated the probabilities of an individual choosing particular alternatives. The Bayesian approach allowed us to compare and update an individual's estimates on the basis of the distribution of preferences from other respondents. Sawtooth uses a Monte Carlo Markov chain to estimate parameters through an iterative process until the model converges at the right distributions of the parameters.³⁵ The individual utility

estimates of each attribute level were averaged after 10,000 random draws. Results are presented as raw utilities and can be interpreted as the attractiveness of each level within the attribute, with higher numbers indicating more attractive options.³⁶ We also estimated the mean importance of attributes across all respondents.

RESULTS

Study Characteristics

Of 262 women approached to participate, 22 (8%) were ineligible (age < 18 years), and 27 (10%) refused (generally because of lack of time). We successfully recruited 213 women; the mean age was 38 years; most women were married and Christian; 64% had no formal or some primary education. Most had low SEP; only 28% had electricity at their residence, and 38% had access to a personal water tap in their homes.

Breast Cancer Knowledge

Fewer than half of the sample (44%) were aware of breast cancer, indicating they had never before heard of the disease. Most women who were aware reported learning about it from a health worker, family member, or friend.

In bivariate analyses (Table 1), women who were aware of breast cancer were more likely to have a higher education level ($P = .002$) and electricity ($P < .001$) and to have had a recent physical examination ($P = .04$). Those who knew any type of cancer survivor were more likely to be aware of breast cancer ($P < .001$). Most known survivors were a relative (41%), friend (26%), neighbor (19%), or parent, spouse, or child (15%). Among peer survivors, cervical cancer and Kaposi's sarcoma (often described as cancer of the leg or skin) were the most common cancer types ($n = 23$ each), followed by breast ($n = 14$) and stomach ($n = 4$); lung, anus, and bladder were each mentioned once. Only one participant reported encountering multiple survivors; only one had a first-degree relative with breast cancer. Breast cancer awareness was positively correlated with BSE awareness ($P < .001$) and CBE awareness ($P < .001$).

In a multivariable model adjusted for marital status, education, and recent physical examination, knowing any cancer survivor (adjusted odds ratio, 4.37; $P < .001$) and having electricity at home (adjusted odds ratio, 3.84; $P < .001$) significantly increased the odds of awareness (Table 2).

We assessed knowledge in more detail among those who were aware of breast cancer (Fig 1).

Table 1. Breast Cancer Survey Sample Characteristics

Characteristic	No. (%)		Total	P
	Not Aware of Breast Cancer	Aware of Breast Cancer		
Total	119 (56)	94 (44)	213 (100)	
Age, years				.10
Mean	37.0	39.6	38.1	
SD	13.8	15.1	14.4	
Religion				.43
Christian	95 (79.8)	80 (85.1)	175 (82.2)	
Muslim	12 (10.1)	9 (9.6)	21 (9.9)	
No religion	12 (10.1)	5 (5.3)	17 (8.0)	
Married	94 (79.0)	83 (88.3)	177 (83.1)	.07
Education level				.002
No formal school	28 (23.5)	14 (14.9)	42 (19.7)	
Primary	60 (50.4)	34 (36.2)	94 (44.1)	
≥ Secondary	31 (26.0)	46 (48.9)	77 (36.1)	
Rural residence	59 (49.9)	36 (37.9)	95 (44.6)	.10
Socioeconomic position				
Electricity	19 (16.0)	41 (43.6)	60 (28.2)	< .001
Personal water tap access	31 (26.1)	49 (52.1)	80 (37.6)	< .001
Health service use				
Physical examination within past 6 months	31 (26.1)	37 (39.4)	68 (31.9)	.04
Cancer awareness				
Aware of peer cancer survivor	22 (18.5)	45 (47.9)	67 (31.5)	< .001

Abbreviation: SD, standard deviation.

Table 2. Associations With Breast Cancer Awareness

Variable	OR (95% CI)	
	Unadjusted	Adjusted
Married	2.00 (0.93 to 4.33)	1.98 (0.87 to 4.51)
Education level		
No formal school (reference)	1.00	1.00
Primary	1.13 (0.52 to 2.44)	0.93 (0.42 to 2.08)
≥ Secondary	2.97 (1.25 to 6.53)	1.61 (0.68 to 3.79)
Electricity	4.07 (2.15 to 7.72)	3.84 (1.91 to 7.71)
Physical examination within past 6 months	1.84 (1.03 to 3.31)	1.40 (0.71 to 2.74)
Aware of peer cancer survivor	4.05 (2.19 to 7.50)	4.37 (2.26 to 8.45)

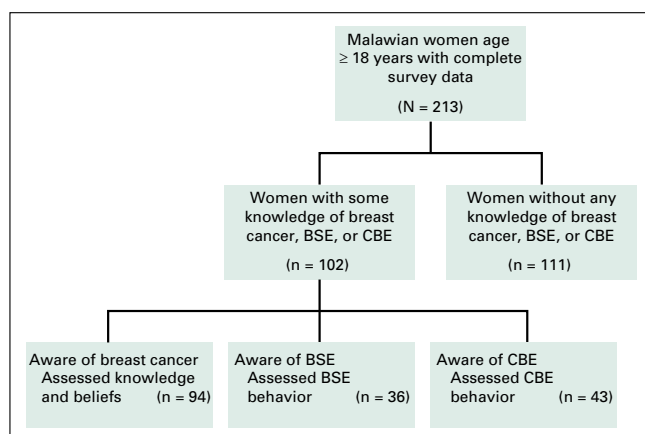
Abbreviation: OR, odds ratio.

Women were more knowledgeable about the signs or symptoms of the disease compared with treatment or risk factors (Table 3). Although 80% correctly identified a lump as a sign or symptom, 11% did not know any signs. Twenty-four percent did not know any correct risk factors, and misconceptions were common (Table 4). For example, many believed storing a cell phone (64%) or money (61%) in a bra could increase risk, and 30% believed breast cancer was contagious. Although most knew surgery to remove the breast was a form of treatment, religious healing practices were also reported.

Beliefs

Women had varying levels of perceived threat of breast cancer (Table 5). Approximately 44% of those who were aware of breast cancer believed they would develop breast cancer at some point in their lifetime; 37% were concerned about their chances of developing breast cancer. Those with a lower education level were more likely to perceive breast cancer as a threat. Half of those aware

Fig 1. Subgroups of survey sample. BSE, breast self-examination; CBE, clinical breast examination.



(n = 47) agreed with all three items on the fear scale. More than half (52%) agreed with at least one of the fatalistic statements about breast cancer diagnosis. Those with a lower education level ($P < .001$) who were not married had more negative beliefs. Women unaware of BSE and CBE had stronger fatalistic beliefs; there were no differences in perceived threat or fear by awareness of early detection behaviors.

BSE

Seventeen percent (n = 36) of the full sample was aware of BSE. Most women learned about BSE from a physician, a family member, a friend, a health talk, or the radio. Among those who knew, 29 (81%) thought performing regular self-examinations would help find cancer early. Twenty-four women (67%) reported performing a self-examination at least once, and 83% reported a physician had motivated them to perform BSE. Women who had performed BSE highly reported benefits, and few barriers were noted (Data Supplement).

CSE

Twenty percent (n = 43) of the full sample had heard of CBE. A physician was the most common information source, followed by a family member, a friend, the radio, a health talk, a religious gathering, and television. Among those who were aware, most women thought CBEs helped find lumps early (91%), decreased the chance of dying as a result of breast cancer (93%), and might help find a lump before a woman could feel it herself (86%).

We explored potential barriers to having a CBE among those who were aware; women reported not knowing where to go (45%) and transportation (30%) as common barriers. Four believed other problems were more important; two women indicated they would be embarrassed about exposing their body.

Few women (n = 14) had ever received a CBE; half of those that were performed had occurred within the past 12 months. Examinations were performed by physicians in private clinics or the central hospital. Four women thought the examination was embarrassing, four said it was uncomfortable, and two thought it was painful. Of the women who had never been examined, additional barriers were identified, including concerns about time, pain, and husbands not approving.

Interest and Acceptability

Nearly all women (n = 206) were interested in learning more about breast cancer. Women wanted

Table 3. Knowledge Among Women Aware of Breast Cancer (n = 94)

Factor	No.* (%)
Sign or symptom	
Lump	75 (80)
Breast pain	67 (71)
Nipple discharge	63 (67)
Nipple discoloration	60 (64)
Skin retraction	58 (62)
Breast discoloration	67 (71)
Change in shape	65 (69)
Itchy nipple	52 (55)
Dimpling (peau d'orange)	53 (56)
Percentage score	
Mean	66.2
SD	37.0
Risk factor	
Family history	45 (48)
Never having children	26 (28)
First delivery after age 30 years	31 (33)
Short breastfeeding duration	27 (29)
Age	28 (30)
Overweight	19 (20)
High fat diet	24 (25)
Alcohol	49 (52)
Percentage score	
Mean	33.1
SD	30.5
Treatment option	
Surgery	76 (81)
Chemotherapy	23 (24)
Hormonal therapy	25 (27)
Percentage score	
Mean	44.0
SD	31.7
Total	
No. correct	
Mean	9.9
SD	4.8
Percentage score	
Mean	49.6
SD	24.2

Abbreviation: SD, standard deviation.

*No. of women who correctly identified each response.

information from a physician (64%), community health worker (40%), radio message (20%),

seminar at church or school (15%), or health talk at a health facility (15%).

All women were asked whether they would adopt BSE if a health worker offered to teach them. Those who were not interested cited being too busy or too old (n = 3), being unable to do it (n = 3), and the ability of a clinician to do it more effectively (n = 2) as reasons for declining. We also asked all women if they would accept a CBE from a health worker, and 96% were interested. Four women said they would refuse because they were too old or not sick.

Preferences Regarding Breast Cancer Detection Services

We examined the proportion of times the attribute levels were selected when they were presented. The shortest travel time was selected most often ($P < .01$), and the community health gathering was the most popular setting (60%; $P < .01$). Physicians were selected 55% of the time. Although respondents favored female health workers, there were no significant differences for sex. The combined early detection strategy of CBE and breast health awareness was selected most often (58%; $P < .01$). There were no differences in preference by breast cancer awareness. Residence was the only demographic characteristic affecting preferences. Urban women were more likely to favor breast health awareness ($P < .01$) and were also more sensitive to travel time ($P < .01$).

Estimated Utilities

We performed multinomial logistic regression with and without interaction terms, which led to similar results and only a slight improvement in model fit. We investigated differences by residence but did not observe significant differences. Therefore, we report the hierarchic Bayesian model with no interactions or covariates (Table 6).

Women valued having a CBE, particularly if it was combined with breast health awareness. Respondents favored shorter travel times and female physicians. They preferred having the intervention available at a FP clinic; interventions offered at a community health gathering were also favored, although not as strongly. Mean importance scores indicated early detection strategy (27%), setting or encounter (24%), and travel time (21%) were the most important attributes; health worker sex and type were less important to women's choices.

DISCUSSION

To our knowledge, this is the first study examining breast cancer and early detection knowledge in

Table 4. Local Misconceptions About Causes and Treatment of Breast Cancer (n = 94)

Misconception	No.* (%)
Risk factor misconception	
Clogged milk	39 (41)
Hybrid chickens	42 (45)
Storing cell phone in bra	60 (64)
Keeping money in bra	57 (61)
Contagious	28 (30)
Treatment misconception	
Herbal medicine	14 (15)
Prayers	44 (47)
Fellowships, healing revivals	28 (30)

*No. indicates the number of women who correctly identified each response.

Malawi and the first DCE eliciting preferences for breast cancer early detection in Africa. More than half of Malawian women surveyed were unaware of breast cancer. Even among those who were aware, knowledge was low. Local misconceptions about causes were common, and few women knew about or exhibited behaviors in line with recommended early detection strategies. Fatalistic beliefs and fear were more common among women with lower SEP and education level. The DCE showed that women preferred a combination of educational and clinical services being available at FP clinics that did not require long travel. These findings provide important insight into intervention and message development.

Our results suggest that widespread breast cancer education is needed. Whereas some studies in African countries have indicated relatively good breast cancer awareness and lower knowledge of risk factors, our findings were similar to reports of rural African subpopulations exhibiting low levels more generally.^{5,6,16} Disseminating information about breast cancer signs and symptoms and encouraging CBE for symptomatic women are essential to avoid overwhelming the already strained health system of Malawi. We emphasize that BSE has never proved effective in reducing mortality,^{37,38} but breast health awareness—encouraging women to be familiar with their breasts and to seek help upon noticing concerns—is important in limited-resource settings.

Knowledge was influenced by social networks. Knowing any type of cancer survivor significantly influenced awareness, and many women had learned about breast cancer from friends or family. Compared with urban Tanzanian women, a

Table 5. Breast Cancer Beliefs Among Malawian Women Aware of Breast Cancer (n = 94)

Belief	No.* (%)
Threat	
Do you think you will get breast cancer in the future?	41 (43.6)
Are you worried about your chances of developing breast cancer in your lifetime?	35 (37.2)
Fear	
When you think about breast cancer, do you feel scared?	57 (60.6)
When you think about breast cancer, do you feel nervous?	72 (76.6)
When you think about breast cancer, do you feel upset?	73 (77.7)
Fatalism	
Do you believe cancer will kill most people who get it?	45 (47.9)
Do you believe if someone gets cancer, it doesn't matter when they find out about it; they will still die of it?	1 (1.1)
Do you believe if someone has cancer, it is already too late to do anything about it?	36 (38.3)

Abbreviation: SD, standard deviation.

*No. of women who responded yes.

greater proportion of our sample knew a survivor, but Malawian women had much lower knowledge.³⁹ Additionally, because fear and fatalism were common in our sample, engaging local survivors may enhance messages about the benefits of early detection. Dispelling misconceptions about causes will be important to address perceived risk. Results also suggest that women of higher SEP (ie, with electricity access at home) are more aware. Targeted communication strategies are needed and must consider communication inequalities, such as access to health information and health literacy, especially in settings like Malawi, where many women have low SEP and little formal education.^{40,41}

Our findings also suggest that early detection could be incorporated into existing health services. Participants preferred having services offered at FP clinics, which likely serve younger women with relatively low breast cancer risk. However, this may have been a natural choice because physical examinations are common at FP clinics and may be associated with preventive care. Interventions offered at other health encounters were not as popular, potentially because of the relevance of certain services, a woman's age or stage of life (eg, number and age of children,

Table 6. Raw Utility Estimates From Discrete Choice Experiment

Attribute or Level	Mean Attribute Importance Score	Mean Level Utility	95% CI
Early detection strategy	26.6		24.83 to 28.30
Breast health awareness		-1.08	-1.23 to -0.93
CBE		0.14	-0.02 to 0.05
Both breast health awareness and CBE		0.94	0.79 to 1.09
Intervention setting/ or encounter	24.3		23.18 to 25.47
Health talk in facility waiting area		-0.11	-0.27 to 0.04
Community health gathering		0.04	-0.19 to 0.27
Cervical cancer screening		-0.13	-0.29 to 0.03
Family planning clinic		0.38	0.21 to 0.56
Well-child age < 5 years visit		-0.19	-0.37 to 0.003
Travel time, hours by foot	21.2		19.53 to 22.80
< 1		0.84	0.69 to 0.99
1-2		-0.06	-0.17 to 0.05
> 2		-0.78	-0.93 to -0.63
Sex of health worker	14.2		12.78 to 16.69
Male		—	
Female		0.20	0.10 to 0.31
Type of health worker	13.7		12.26 to 15.15
Physician		0.52	0.41 to 0.62
Health surveillance assistant		—	

NOTE. We used effects coding (ie, the last level within each attribute was not included in the model but was estimated as the negative sum of the other attribute levels). Attributes are listed in order of importance. Preferred attribute levels are bolded; higher numbers indicate attractiveness.

Abbreviation: CBE, clinical breast examination.

menopausal status), or awareness of other cancers and screening services. Additional research on the optimal packaging of women's health services is needed.

The results also indicate that access to and convenience of interventions are important. Travel time influenced preferences, and transportation was identified as a barrier to having a CBE. In prior research among Malawian patients with breast cancer, we also found that structural, health system, and health worker factors delayed diagnosis and treatment.¹⁹ Transportation, cost of care, and access to providers delayed cancer help-seeking behaviors in other African countries.⁴² Our results confirm that structural barriers affect cancer behaviors and preferences for services.

Distributing services throughout lower-level health centers in urban and rural communities will be critical. System-level interventions must coincide with workforce training to ensure access to accurate cancer information, high-quality CBEs, and timely follow-up.¹⁹ Studies in Malawi and other African settings have suggested that lay health workers may be a promising option for breast cancer education and conducting CBEs.^{43,44}

Although we expected women to have stronger preferences for health worker sex on the basis of the DCE development,³³ the results demonstrate that sex is not as important as other intervention attributes. Having a female physician may enhance the experience but not affect a woman's willingness to participate. Instead, women highly valued CBE and were willing to make tradeoffs, which may be a result of paternalistic norms regarding health workers and patients feeling like they do not have the option of requesting a woman.³³

This study has some limitations, including that our sample was drawn from one district in Malawi and may not be generalizable to other settings. However, Lilongwe is diverse in terms of tribal background, religion, and education. Limited breast cancer knowledge may mean that our sample values intervention attributes differently than women who are more aware of breast cancer. Evidence for the effect of experience on preference patterns is mixed; some studies have indicated preference differences for experienced versus naïve respondents.^{45,46} Although we did not observe differences by breast cancer awareness, additional research on the influence of awareness of other common cancers is needed, especially given the burden of AIDS-defining cancers and campaign efforts.

In conclusion, interventions are needed to address low knowledge of breast cancer and early detection strategies, especially among low SEP women. Educational messages must address local fears and misconceptions about risk factors and curability. Programs may be more successful if they are tailored to women's preferences and overcome access barriers, such as bundling breast health awareness and CBEs with other services in convenient settings that do not require substantial travel. Improving knowledge and increasing access to CBEs through existing health services have potential to make a significant impact on cancer burden.

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