

Breast Cancer Beliefs as Potential Targets for Breast Cancer Awareness Efforts to Decrease Late-Stage Presentation in Uganda

abstract

Purpose To assess breast cancer beliefs in Uganda and determine whether these beliefs are associated with factors potentially related to nonparticipation in early detection.

Methods A survey with open- and close-ended items was conducted in a community sample of Ugandan women to assess their beliefs about breast cancer. Linear regression was used to ascertain associations between breast cancer beliefs and demographic factors potentially associated with early detection, including socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices.

Results Of the 401 Ugandan women surveyed, most had less than a primary school education and received medical care at community health centers. Most women either believed in or were unsure about cultural explanatory models for developing breast cancer (> 82%), and the majority listed these beliefs as the most important causes of breast cancer (69%). By comparison, ≤ 45% of women believed in scientific explanatory risks for developing breast cancer. Although most believed that regular screening and early detection would find breast cancer when it is easy to treat (88% and 80%, respectively), they simultaneously held fatalistic attitudes toward their own detection efforts, including belief or uncertainty that a cure is impossible once they could self-detect a lump (54%). Individual beliefs were largely independent of demographic factors.

Conclusion Misconceptions about breast cancer risks and benefits of early detection are widespread in Uganda and must be addressed in future breast cancer awareness efforts. Until screening programs exist, most breast cancer will be self-detected. Unless addressed by future awareness efforts, the high frequency of fatalistic attitudes held by women toward their own detection efforts will continue to be deleterious to breast cancer early detection in sub-Saharan countries like Uganda.

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INTRODUCTION

In low- and middle-income countries (LMICs) such as Uganda, breast cancer mortality is a significant public health problem.¹ More than three fourths of patients are diagnosed with late-stage disease (stages III and IV),^{2,3} which is associated with greater social stigma, more-expensive treatment, and poorer survival.^{4,5} Similar to other LMICs, the increasing incidence and mortality of breast cancer in Uganda is an enormous economic burden and has the potential to overwhelm an already limited health care budget.^{6,7}

We previously showed that a minority of Ugandan women participate in breast cancer downstaging practices, despite receipt of breast cancer

education.⁸ The Breast Health Global Initiative, an organization focused on providing resource-stratified guidelines to improve survival in LMICs,⁹ recommends an understanding of local beliefs about breast cancer as a prerequisite for effective early breast cancer detection programs.⁵ Indeed, beliefs help to guide health behavior but can be problematic when not grounded in scientific evidence and obstruct health-seeking behavior. Current efforts that promote breast cancer awareness in Uganda occur through television and radio commercials and health fairs run by village health teams. Village health teams comprise elected community volunteers who are taught health information by a clinical provider from the community health center to deliver to their villages.¹⁰ Current

breast health information is derived from information obtained from foreign countries and a few studies done at national referral hospitals (Mulago Hospital and Uganda Cancer Institute). A misunderstanding of the implications of beliefs may help to explain why current education efforts that reach approximately 50% of the population have failed to change health behavior or reduce late-stage presentation in Uganda.⁸

Few studies have addressed breast cancer beliefs in sub-Saharan Africa and how these beliefs contribute to late-stage presentation.¹¹ These and cross-cultural studies on beliefs related to late-stage presentation show common themes, including fear related to treatment (eg, disfigurement from mastectomy), fear of isolation (eg, divorce), and belief that cancer is contagious or a supernatural act (eg, punishment from God).^{12,13} However, these studies also highlight unique cultural beliefs to be addressed in effective awareness efforts to reduce late-stage presentation. Two studies that described breast cancer beliefs in Uganda through qualitative interviews with breast cancer survivors suggested that widespread beliefs in cultural explanatory models for developing breast cancer (eg, carrying a cell phone in one's bra) may limit women's participation in early detection efforts.^{14,15} This gap in knowledge in some countries has resulted in ineffective one-size-fits-all breast health communication and a low participation rate in early detection.¹⁶ Additional studies to understand the cultural beliefs in Uganda that contribute to late-stage presentation in a community sample of Ugandan women would help to guide more-effective breast cancer awareness.

Previous work also did not study associations between breast cancer beliefs and demographic factors potentially associated with early detection, including socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices. Such associations are required to identify health disparities among at-risk subpopulations and develop subgroup-specific interventions. Although not studied in the context of beliefs, socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices determine when and how sub-Saharan women seek medical care.^{14,17-19} Studies in other sub-Saharan African countries show that these factors are associated with breast cancer beliefs,^{17,20,21} possibly because women with certain socioeconomic factors, health care access, prior breast cancer exposure, and personal detection practices may be disproportionately targeted for educational outreach. For example, women with

similar religious beliefs form strong social networks in Uganda, and these networks could be an opportunity to promote breast awareness and increase acceptance of a breast cancer diagnosis and the likelihood of pursuing treatment.¹⁵ The identification of subpopulations of women most likely to hold beliefs about breast cancer will help to inform efforts by the Ugandan Ministry of Health to improve breast cancer awareness.

To address these gaps in the literature, and as a first step to designing useful education, we assessed Ugandan women's breast cancer beliefs and tested associations between these beliefs and socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices that potentially contribute to the average 2-year delay in seeking medical care after self-detecting a breast lump. These data will provide essential information to the design of better breast health communication to reduce late-stage breast cancer presentation.

METHODS

Participants and Setting

This study was conducted in close collaboration with the Ugandan Women's Cancer Support Organization (UWOCASO) between January and July 2014. UWOCASO is a volunteer group of breast cancer survivors who provide education and organize community fund-raiser activities for breast cancer control. UWOCASO helped to select the study geographic areas on the basis of population density. With the assistance of local community leaders, we used convenience-based sampling in the marketplace and homes to recruit women from the largest urban center, Kampala (population density, 24,423 people per square mile), and from the villages and communities in south central Uganda (population density, one to 500 people per square mile).²²

Data Collection

Assisted by local community leaders, UWOCASO recruited women age ≥ 25 years with no personal history of breast cancer. UWOCASO women with previous experience received additional training with this survey before interviewing. Participants were interviewed individually in a semiprivate area and were given 10 US dollars to complete a 30-minute survey. This study was exempt from full institutional review board review because it extracted data from anonymous surveys.

Measures

The creation and pilot testing of the Attitudes on Breast Cancer Surveillance and Knowledge survey

has been described previously.⁸ Briefly, we used standard methods of cross-cultural adaptation and development of surveys.²³⁻³² We reviewed previously published data from two studies,^{14,33} findings from three focus groups guided by trained facilitators, and recommendations of a panel of cultural experts to select content for survey items related to breast cancer beliefs in Uganda. From this content, we selected items from a validated instrument after small modifications to account for cultural differences.³⁴ These items were tested iteratively, modified with the guidance of cultural and survey experts, and cognitively tested in UWOCASO women.³⁵ The final Attitudes on Breast Cancer Surveillance and Knowledge survey was translated from English (primary language) to Luganda (common local language).

Beliefs. Fourteen items related to breast cancer beliefs were included in the survey: Five assessed beliefs in cultural explanatory models for developing breast cancer, three assessed beliefs in scientific explanatory risks for developing breast cancer, and six assessed beliefs in the benefits of early detection. For each item, we recoded responses (disagree, unsure, and agree) to correct, unsure, and incorrect. Participants also were asked to list what they believed were the three most common causes of breast cancer (free response).

Socioeconomic factors. Socioeconomic variables were age (continuous variable), geographic region (urban, rural), ethnicity (Bantu, other), religion (Christian, other), intimate partner status (married/living with partner, other), education (primary or less, more than primary), and income (\leq 500,000 shillings, $>$ 500,000 shillings). An annual salary of 500,000 shillings is 33% below the poverty line and was chosen as the threshold because it divided the surveyed population in half.

Health care access. Health care factors included where participants received most of their health care (community health center, regional/referral hospital, self-care at home, other) and how they usually paid for this care (self-pay, government/subsidized, other). Those who reported more than one method for their health care payment were placed in the other category.

Prior breast cancer knowledge. Participants reported whether they had a family history of breast cancer (yes, no) and whether they had ever received breast cancer education (yes, no).

Personal detection practices. Participants reported their lifetime history of examining or observing their

own breasts for palpable lumps (ever, never) and whether they had undergone a clinical breast examination by a health provider in the past year (yes, no).

Data Management and Analysis

The collaborative data services shared resource at the Fred Hutchinson Cancer Research Center entered the survey data by using the Illume software package (DatStat, Seattle, WA). Psychometric analysis confirmed that items tapped into several constructs (eg, Cronbach's $\alpha < .7$). Therefore, we analyzed each item separately for associations with demographic factors rather than by grouping items as indices or scales on the basis of belief categories. For our analysis, we combined the incorrect responses with the unsure responses to differentiate between correct responses and other responses. We then used linear regression to ascertain associations between responses for each item and socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices. To limit the possibility for type I error from multiple analyses, we considered $P < .001$ as significant. All statistical analyses were performed with SPSS software (version 19, IBM Corporation, Chicago, IL).

RESULTS

A total of 401 women participated in this survey, with 100 from the capital city and largest metropolitan area of Uganda (Kampala) and 301 from rural villages and communities in South Central Uganda (Rakai District). Table 1 lists the characteristics of the surveyed population. Mean age was 41 years. Most participants were Bantu (89%), Christian (84%), married or living with a partner (63%), and had a primary education or less (66%). In terms of health care, participants were distributed evenly among self-care at home (29%), community health center (33%), and regional/referral hospital (29%). Most (69%) self-paid for their health care. The majority of participants had no family history of breast cancer (86%) and had not received prior breast cancer education (53%). Most had never examined their own breasts for lumps (73%) and had not received a clinical breast examination in the previous 12 months (85%).

Frequency of Breast Cancer Beliefs

Table 2 lists breast cancer beliefs among this community sample of Ugandan women. Most participants ($> 84\%$) either believed in or were uncertain about individual beliefs related to cultural explanatory models for developing breast cancer

Table 1. Population Characteristics

Characteristic	No. (%)
Total population	401
Socioeconomic factors	
Mean age, years (SD)	41 (10)
Geographic location	
Urban	100 (25)
Rural	301 (75)
Ethnicity	
Bantu	355 (89)
Other	42 (11)
Religious group	
Christian	336 (84)
Other	65 (16)
Intimate partner status	
Married/living with partner	247 (63)
Other	148 (37)
Education	
Primary or less	265 (66)
More than primary	135 (34)
Income, shillings	
≤ 500,000	150 (50)
> 500,000	147 (50)
Health care access	
Regular source of care	
Self-care at home	115 (29)
Regional/referral hospital	115 (29)
Community health center	130 (33)
Other	36 (9)
Usual form of payment for care	
Self-pay	274 (69)
Government/subsidized	171 (43)
Other	12 (3)
Prior breast cancer knowledge	
Family history of breast cancer	
Yes	52 (14)
No	327 (86)
Received breast cancer education	
Yes	181 (47)
No	204 (53)
Personal detection practices	
Performed breast self-examination	
Ever	103 (27)
Never	284 (73)
Clinical breast examination ≤ 12 months	
Yes	61 (15)
No	335 (85)

Abbreviation: SD, standard deviation.

(items 1 to 5). In particular, beliefs or uncertainty related to bras as a cause of breast cancer were particularly common among Ugandan women ($\geq 95\%$). Although many (35% to 45%) endorsed individual beliefs related to scientific explanatory risk factors for developing breast cancer (items 6 to 8), most were uncertain or did not believe in these factors, including 32% who believe that breast cancer only occurred in women older than 40 years. Participants similarly showed variability in incorrect and uncertain responses to individual beliefs about the benefits of early detection (items 9 to 14). Most believed that early detection and regular screening for breast cancer would result in a cure if breast cancer was detected (80% and 88%, respectively), but many simultaneously thought of death when they thought about breast cancer (76%), believed or were uncertain about whether most breast lumps represented cancer (70%), and believed that breast cancer self-detected as a lump was too late to cure (54%).

Most Important Perceived Causes of Breast Cancer

Table 3 lists the frequency of the three most important culturally perceived risks of breast cancer (women's perspective). Almost one half of the participants (47%) believed that wearing bras or sharing bras and carrying items in bras caused breast cancer. Approximately 17% listed scientific explanatory risk factors as one of the top three causes for developing breast cancer, including only three women who listed older age.

Variation in Breast Cancer Beliefs by Demographic Factors

Using bivariate linear regression models, we analyzed socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices for predictors of individual beliefs (data not shown). Only not having prior breast cancer education (ie, carrying a phone in the bra causes cancer) was significantly associated with a belief ($P < .001$).

DISCUSSION

We assessed Ugandan women's breast cancer beliefs to understand the average 2-year delay in seeking medical care after self-detecting a breast lump. The understanding of these beliefs will help to inform educational interventions to reduce late-stage presentation and diagnosis. We found widespread beliefs in cultural explanatory models for developing breast cancer; these beliefs were largely independent of

Table 2. Frequency of Incorrect Breast Cancer Beliefs

Belief (correct answer)	Incorrect, No. (%)	Unsure, No. (%)	Correct, No. (%)
1. A hard blow may cause cancer.	207 (52)	141 (35)	53 (13)
2. Carrying money in the bra can cause cancer.	328 (82)	61 (15)	10 (3)
3. Carrying a cell phone in the bra can cause breast cancer.	283 (71)	106 (26)	9 (2)
4. Sharing bras may cause breast cancer.	270 (67)	109 (27)	19 (5)
5. Cancer can be caused by not taking care of one's self.	248 (62)	80 (20)	69 (17)
6. Being overweight increases the risk of developing breast cancer.	61 (15)	157 (39)	179 (45)
7. Having your first child after 30 years of age increases your risk of breast cancer.	66 (17)	190 (47)	141 (35)
8. Breast cancer can occur in women younger than 40 years.	128 (32)	88 (22)	181 (45)
9. Most breast lumps are cancerous.	162 (41)	115 (29)	117 (30)
10. For many women, breast cancer can be successfully treated.	76 (19)	77 (19)	243 (61)
11. By the time a woman can feel a breast lump, it is too late to cure.	137 (34)	82 (20)	170 (42)
12. Getting checked regularly for breast cancer can help to find cancer when it is easy to treat.	18 (5)	31 (8)	351 (88)
13. Breast cancer is an illness that when detected early can usually be cured.	27 (7)	53 (13)	319 (80)
14. When I think of breast cancer, I automatically think of death.	305 (76)	10 (3)	85 (21)

NOTE. Items 1 to 5: cultural explanatory models for developing breast cancer. Items 6 to 8: scientific explanatory risks for developing breast cancer. Items 9 to 14: perceived benefits of early detection.

socioeconomic factors, health care access, prior breast cancer knowledge, and personal detection practices. We also found that many women did not believe in or were uncertain about scientific explanatory risk factors for developing breast cancer, and many perceived few benefits of early detection. In addition, the receipt of previous breast cancer education was not associated with a significant change in many beliefs, which suggests that current breast cancer education efforts are inadequate.

Beliefs in cultural explanatory models for developing breast cancer emerged as particularly important to future interventions for increasing breast cancer awareness. Of note, no participant correctly rejected all cultural explanatory models for developing breast cancer. Similar to a previous study, we specifically found that carrying items in bras, the use of steel brushes to clean pots, and breast trauma were commonly held etiologic beliefs about breast cancer in Uganda.¹⁴ These beliefs in culturally perceived risks are related to

new practices introduced during the westernization of Ugandan culture, which has occurred relatively recently. This westernization period also corresponds to the period when many Ugandans have observed a rapid increase in breast cancer. An underlying premise seems to be that breast cancer is contagious and that wearing used bras, particularly those donated from white women (who have a high incidence of breast cancer) in Western countries, is considered to cause breast cancer. These findings suggest that future education must dispel cultural explanatory models for developing breast cancer and increase awareness about modifiable scientific explanatory risks associated with westernization, such as early menarche, late menopause, low parity, and obesity.³⁶ These findings also support the involvement of local non-Western stakeholders in breast cancer awareness efforts to promote scientifically established risks and to dispel beliefs about contracting breast cancer from Westerners or Western items.

An essential component of raising breast cancer awareness includes the belief that breast cancer is survivable and that early detection increases chances of survival. Early detection efforts are particularly important in countries, like Uganda, without screening programs or access to mammography. Wider variation exists with regard to the beliefs in the benefits of early detection relative to other beliefs. Specifically, we found that most participants believed that early detection and treatment save lives; however, they simultaneously believed that most breast lumps represent breast cancer and that a self-detectable breast lump meant that cure was unlikely. Although not significant in our analysis ($P < .001$), poorer older women who had not performed breast self-examination, received prior breast cancer education, or selected self-care as their regular source of care trended toward higher fatalism in their own detection efforts, and women with higher incomes showed stronger beliefs in the benefits of early detection ($P < .05$). Previous studies have shown that this fatalism in one's own detection efforts can prevent or delay the seeking of care after self-detecting symptoms.^{37,38} These beliefs may help to explain why women wait an average of 2 years after self-detecting a breast lump before seeking medical care.³⁹ Breast cancer education and awareness efforts must change women's perceived benefits of early detection because breast cancer is survivable, even in low-resource areas, if treatment is started at an early stage. The suggestion that fatalism may underlie late-stage presentation emphasizes the importance of involving healthy

Table 3. Most Important Perceived Cause of Breast Cancer

Cause	No. (%)
Bra related*	363 (46.7)
Infection*	80 (10.3)
Environmental exposure*	63 (8.1)
Trauma*	33 (4.1)
Overweight	45 (6)
Child related (eg, breastfeeding, having child after 30 years of age)†	43 (6)
Older age†	3 (0)
Exogenous hormones†	24 (3)
Genetics/inherited†	15 (2)
Unknown	52 (6.7)
Other	25 (3.2)

Notes. More than one free response per participant was allowed. Participants listed 2-3 “most important” causes of breast cancer if they could not list just one.

*Represents cultural explanatory model for developing breast cancer.

†Indicates scientific explanatory risk factors for developing breast cancer.

breast cancer survivors in future breast cancer awareness efforts.

Many of our survey items have been used successfully in other cultures to identify breast cancer beliefs. However, the application and results of surveys are limited by cultural context. For example, several women listed inherited/genetics as a scientific explanatory risk for developing breast cancer, but in deeper discussions, they said that they really believed they could inherit breast cancer as a curse from an enemy. Similarly, many participants believed that trauma caused breast cancer, yet those who elaborated on the trauma specifically referenced domestic violence. These beliefs in cultural explanatory models for developing breast cancer clarify the social stigma that influences a woman’s decision not to talk about having breast lumps or to seek medical care. The cultural subtleties show the importance of collaborating with health leaders. For this study, we collaborated with the only Ugandan breast cancer survivors group UWOCASO. UWOCASO women were involved in all aspects of this study from the conceptual design and survey development to the data collection, analysis, and interpretation to ensure that the appropriate cultural context is represented in this study and in planning future breast cancer awareness efforts. The involvement of these cultural and health leaders included one author (J.R.S.) who presented the initial results and received comments and interpretations from six UWOCASO women. Future breast cancer

awareness will involve these health leaders to target common beliefs and misconceptions about breast cancer to reduce late-stage presentation.

This study is limited by its convenience-based sampling. However, we targeted centers in urban and rural settings where mostly poor residents with less than a primary school education live. Because most Ugandans are poor or vulnerable to poverty and have little education,^{40,41} we believe that our study population is generalizable to the Ugandan population. The number of items and constructs assessed in the current study were focused on beliefs that contribute to late-stage presentation. We derived the items about beliefs used in this study from previously published studies and focus groups that comprised breast cancer survivors and further supplemented the yes/no items with free-response items. We identified few additional beliefs (3.2%) in our free-response items not covered in our closed-ended items. Thus, we believe that we comprehensively assessed the beliefs related to breast cancer cause and benefits of early detection. Future studies should address other constructs that may affect breast cancer morbidity and mortality, including barriers to presenting early and family/social network support for participating in breast cancer awareness and early detection practices, as well as how breast cancer stigma may affect late-stage presentation. Finally, although we obtained similar results when analyzing our items as indices (ie, cultural explanatory models for developing breast cancer, scientific explanatory risk factors for developing breast cancer, perceived benefits in early detection), we show our final analysis as individual items to reduce possible confusion with a validated scale. Future research that uses validated scales is warranted to confirm our findings.

In summary, we assessed breast cancer beliefs among Ugandan women. We show that despite receipt of previous breast cancer education, most women still hold beliefs that may prevent them from seeking care early after self-detecting a lump. In particular, fatalism with regard to a woman’s own self-detection efforts should be addressed in future early breast cancer detection programs.

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