Patient Factors Contributing to Late-Stage Breast Cancer Presentation

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Abstract

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Purpose

To assess factors contributing to the late-stage breast cancer presentation in Uganda.

Methods

A survey with open and close-ended questions was conducted on a community sample of Ugandan women to assess 1. Breast cancer downstaging practices and breast health messaging preferences to present early for a CBE in the theoretical scenario of self-detecting a palpable lump (breast health messaging preferences) and 2. Their beliefs (culturally-perceived risks, scientifically-established risks, perceived benefits of early detection) about breast cancer.

Results

The 401 Ugandan women who participated in this survey were mostly poor with less than a primary school education. Of these women, 27% had engaged in BSE and 15% had undergone a CBE. Greater breast cancer downstaging practices were associated with an urban location, higher education, having a health center for their regular source of care and receiving breast cancer education ($P<0.05$). Women indicated a greater breast health messaging preference from

their provider (66%). This preference was associated with a rural location, having a health center for their regular source of care, and receiving breast cancer education ($P<0.05$). Culturally-perceived risks of breast cancer were common (58.5-97.7%) and were described by the majority as the most important causes of breast cancer (69.2%), compared to scientifically-established risks (45.6-64.5%; 16.2%, respectively). Perceived benefits of early detection varied widely (12.3-70.3%) while many women held fatalistic attitudes towards their own detection efforts, including the common belief that cure is impossible once they could self-detect a lump (56.3%). Only having a lower income was associated with all breast cancer belief categories.

Conclusion

Current breast cancer education in Uganda is inadequate; most Ugandan women do not participate in breast cancer downstaging practices despite receiving breast cancer education. 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 towards their own detection efforts will continue to be deleterious to breast cancer early detection in sub-Saharan countries like Uganda.

Chapter 1

Breast Cancer Downstaging Practices And Breast Health Messaging Preferences Among A Community Sample Of Urban And Rural Ugandan Women

Abstract

Purpose: Among a community sample of Ugandan women, we provide information concerning breast cancer downstaging practices (breast self-exams, BSE; clinical breast exams, CBE) and breast health messaging preferences across socio-demographic, healthcare access, and prior breast cancer exposure factors.

Methods: Convenience-based sampling was conducted to recruit a sample of Ugandan women aged 25 years and older to assess breast cancer downstaging practices as well as breast health messaging preferences to present early for a CBE in the theoretical scenario of self-detecting a palpable lump (breast health messaging preferences).

Results: The 401 Ugandan women who participated in this survey were mostly poor with less than a primary school education. Of these women, 27% had engaged in BSE and 15% had undergone a CBE. Greater breast cancer downstaging practices were associated with an urban location, higher education, having a health center for their regular source of care and receiving breast cancer education ($P<0.05$). Women indicated a greater breast health messaging preference from their provider (66%). This preference was associated with a rural location, having a health center for their regular source of care, and receiving breast cancer education ($P<0.05$).

Conclusions: Most Ugandan women do not participate in breast cancer downstaging practices despite receiving breast cancer education. However, receiving such education increases downstaging practices and preference for messaging from their provider. Therefore, efforts to downstage breast cancer in Uganda should simultaneously raise awareness in providers and support improved education efforts in the community.

Introduction

Breast cancer incidence in Uganda, like many other low- and middle-income countries (LMICs) in sub-Saharan Africa (SSA), has been increasing by a staggering 5.2% per year for the past 15 years.[1] Unlike most SSA countries, Uganda offers cancer treatment including surgery, radiation and chemotherapy at no cost at the Ugandan Cancer Institute (UCI) through a collaborative arrangement with the Ugandan Ministry of Health, the U.S. National Cancer Institute and the Fred Hutchinson Cancer Research Center.[2] Nonetheless, late-stage presentation is a primary obstacle to improving breast cancer outcomes in Uganda, where >77% of women are diagnosed with advanced staged disease, including 26% with metastatic Stage IV cancer at initial presentation.[3,4] In a recent analysis of breast cancer patients treated at UCI, 187 patients presented with stage III or IV disease and had a less than 40% chance of surviving 5 years; by contrast, no deaths occurred at 5 years for the 22 patients who presented initially with stage I or II disease.[4] Thus, understanding those systems-based factors that contribute to late stage presentation and may promote breast cancer downstaging is important to improving outcomes in Uganda and potentially other SSA countries where breast cancer treatment can be available.

In LMICs where population-based screening is neither practical nor affordable, early breast cancer detection requires active participation by both patients and the healthcare system. According to guidelines from the American Cancer Society,[5] the National Comprehensive Cancer Network (NCCN),[6,7] and the Breast Health Global Initiative (BHGI),[8] the importance of prompt reporting of new breast symptoms to a health professional should be emphasized. This requires breast awareness, meaning that a woman should be able to identify significant changes in her breasts and needs to know that reporting these self-detected abnormalities can improve breast cancer outcome. In parallel, these women need access to clinics that can perform diagnostic work-ups to distinguish benign findings from cancers promptly.[9] Thus, the

evaluation of practices that reflect breast awareness education and clinical diagnostic services is relevant to improving downstaging.

Neither teaching breast self-examination (BSE) nor performance of clinical breast examination (CBE) has been demonstrated in a screening setting to independently reduce breast cancer mortality.[10,11] Nonetheless, for countries like Uganda, where women commonly first present with visually obvious breast masses or ulcerated tumors that have been present for many months or years, the assessment of BSE and CBE practices can serve as surrogate measures for essential factors contributing to or defeating breast cancer downstaging. Recent work in rural Ghana has shown that breast cancer awareness education is associated with increased self-reported BSE and may link to improved breast cancer early detection and downstaging.[12] Similarly, CBE is necessary for diagnostic evaluation of clinically detectable masses and thickenings and is a basic level resource for breast diagnosis in health settings at all economic levels.[6,7,9] Thus, the measurement of BSE and CBE practices is relevant proxy for patient-determined (BSE) and clinic-determined (CBE) breast cancer downstaging practices in a LMIC where breast cancer screening is unavailable. Furthermore, understanding how breast health messaging preferences related to these factors vary across socio-demographic, healthcare access, and prior breast cancer exposure factors can inform future approaches and programs to better target downstaging among women who have access to treatment.

This study had these objectives: 1) to provide information concerning downstaging practices and breast health messaging preferences among Ugandan women 25-65 years old; and 2) to examine downstaging practices and breast health messaging preferences across socio-demographic, healthcare access and prior breast cancer exposure factors.

Methods

Procedures

This study was conducted between January and July 2014 in close collaboration with the Ugandan Women's Cancer Support Organization (UWOCASO), a local group of breast cancer survivors. These Ugandan women are familiar with Ugandan culture and also have experience administering survey instruments and providing breast cancer education. After developing the survey through multiple iterations and translating it from English (primary language of Uganda) to Luganda (common local language), we piloted the survey among a group of UWOCASO workers.

This study was exempt from Ugandan and U.S. IRB review. Local guides and UWOCASO workers recruited women from the community for this study. We included asymptomatic women ≥25 years with no personal history of breast cancer. Trained UWOCASO members interviewed eligible women individually in a semi-private area. Participating women received a small financial incentive for their time and effort in accordance with local recommendations.

Participants and Setting

We collected survey data from 401 participants: 100 from the capital city and largest urban center, Kampala (Kamwonkya (N = 50) and Namuwongo (N = 50) communities), and 301 from rural villages and communities in South Central Uganda (Rakai district: Kakuuto County) (Ssanje Community, N = 100 and Manya Parish, N = 100) and Kooki County (Lwanda Parish, N = 100). The population densities were 24,423 people/square mile for the urban centers and ranged from <50 people/square mile (Kakuuto County) to 251-500 people/square mile (Kooki County) for the rural centers.[13]

Measures

Socio-demographic, healthcare access, and prior breast cancer exposure factors. Socio-demographic information included: geographic region (urban, rural), age (25-39, 40-49, 50-74), ethnicity (Bantu, Other), religion (Christian, Other), intimate partner status (Marital/Living with Partner, Other), education (≤ Primary [7 years or less], >Primary [more than 7 years]), and income (≤ 5000,000 Shillings, >500,000 Shillings). The annual income question was re-categorized into a bivariate response because few participants reported income greater than the poverty level (approximately 1.5 million shillings/year).[14,15] For healthcare access factors, women reported their regular source of care (Health Center, Other [e.g., self care at home, traditional healer]) and their usual form of payment for care (Self-pay, Charity Care, Other [e.g. private health insurance]). For prior breast cancer exposure, women self-reported whether they had a family history of breast cancer (no, yes) and whether they had ever received breast cancer education (no, yes).

Breast cancer downstaging practices. Women reported their lifetime history of examining or observing their own breasts for palpable lumps (BSE: never, ever) and if they had undergone a CBE by a health provider in the past year (no, yes).

Breast health messaging preferences. Women indicated whose advice would most influence them most in presenting early for a CBE in the theoretical scenario of self-detecting a palpable lump. Response categories included health providers, family/friends and societal sources (advertisement by the government, TV or radio). Women were also asked where they would choose to go for a CBE (local health clinic, regional referral hospital, or other [e.g., no preference, abroad]).

Data Collection and Analysis

The Collaborative Data Services at the Fred Hutchinson Cancer Research Center entered the questionnaire data using the DatStat Illume software package (Seattle, WA). We produced descriptive information concerning downstaging practices and breast health messaging preferences. We conducted chi-square tests to examine the relationships of downstaging practices and healthcare messaging preferences across socio-demographic, healthcare access, and prior breast cancer exposure factors. All statistical analyses were performed with IBM SPSS (Chicago, SPSS Inc.).

Results

Table 1 summarizes socio-demographic factors and health care factors. The median age for the 401 surveyed women was 38 years (25-74). Most women were married or living with a partner (62%), had a primary education or less (66%), and had an annual household income below the 33% poverty line (50%). Most participants reported receiving medical care from a health center (61%) and self-paying for their care (67%). For prior breast cancer exposure, 14% reported a family history of breast cancer and 47% self-reported receiving previous breast cancer education.

Frequency of downstaging practices and healthcare preferences

Table 2 depicts information concerning downstaging practices and breast health messaging preferences. Overall, the sample had low levels of downstaging practices: 27% had performed a BSE at least once in their lifetime and 15% had received a CBE in the past 12 months. Variability was found regarding breast health messaging preferences: Women reported the greatest preference for breast health messaging by their healthcare provider (66%) followed by friends/family (23%). Women preferred receiving a CBE at a regional referral hospital (51%) to a local health clinic (12%).

Variation of downstaging practices and breast health messaging preferences across socio-demographic, healthcare access and prior breast cancer exposure factors

We next analyzed the distribution of downstaging practices across socio-demographic, healthcare access, and prior breast cancer exposure factors (Table 3). Based on geographic region, urban participants were significantly more likely to report performing BSE (46% versus 20%, P=<.001), and having a CBE in the past 12 months (34% versus 9%, P=<.001) than their rural counterparts. Participants with more than a primary school education were more likely to perform BSE (39% versus 21%, P=<.001). Women receiving regular care at the health center also were more likely to receive a CBE in the past 12 months (20% vs. 9%, P=.004). Women receiving previous breast cancer education showed significantly higher downstaging practices for both BSE (37% vs. 18%, P=<.001) and CBE (27% vs. 5%, P=<.001). No significant difference was found in downstaging practices related to age, marital status, income, usual pay and family history.

We also analyzed breast health messaging preference across socio-demographic, healthcare access and prior breast cancer exposure factors (Table 4). Relative to urban counterparts, a greater proportion of rural women indicated they preferred breast health messaging from their provider (69% versus 56%; P= <.001). Conversely, urban women showed greater preference for breast health messages from societal factors after self-detecting a palpable lump (24% vs. 7%; P= <.001). With regard to healthcare access factors, women who reported health centers as the regular source of healthcare showed greater preference for breast health messaging from their health providers (72% vs. 57%; P=0.005). Women who self-paid for healthcare showed less preference for breast health messaging from their health providers, compared to women who paid using other means, (62% vs. 71-75%; P = .048), and greater preference for breast health messaging from family/friends (28% vs. 9-16%; P=.048). Women

who report receiving breast cancer education showed greater preference for breast health messages from their health providers, compared to women reporting no breast cancer education (70% vs 58%; P= .021), and less preference from family/friends (18% vs. 30%; P= .021).

Discussion

Breast cancer is a growing problem in Sub-Saharan Africa and has the potential to overwhelm limited resources .[16,17] The increasing incidence of breast cancer in LMICs places an enormous burden on individuals and their families in an already taxed health care system.[18,19] For these reasons, the World Health Organization is leading efforts to reduce this avoidable late disease burden by 2025.[20] Breast cancer treatment is available in Uganda, but these efforts are thwarted by late-stage presentation when 75-90% of such women are diagnosed with locally advanced (Stage III) or metastatic (Stage IV) disease.[3,21] Such late stages are associated with more costly and technically demanding treatment and poorer survival even in the United States where the latest treatment options are available.[9,22] Therefore, efforts should focus on detecting breast cancer at an earlier stage (downstaging).[23-25]

To inform interventions to improve outcomes, we surveyed Ugandan women to assess their baseline downstaging practices and breast health messaging preferences and to examine variations in these downstaging practices and breast health messaging preferences across socio-demographic, healthcare access and prior breast cancer exposure factors. Uganda was chosen as the study site because the Ugandan Cancer Institute offers breast cancer treatment at no cost to the patient. Unfortunately, improved access to treatment is not as effective against late-stage breast cancer as early-stage breast cancer. Therefore, downstaging is a prerequisite because early-stage breast cancer is more realistic to treat and with improved outcomes in a limited resource setting.[24,26,27]

Before designing interventions, it is valuable to understand the populations' baseline

experiences with downstaging practices and health messaging preferences.(e.g., providers, family, friends) likely to be effective.[28,29] Two previous studies suggest the majority of Ugandan women performed a BSE at least once and almost half received a CBE in the past year.[30,31] Both of these studies were limited in their generalizability to the Ugandan population, with one study focused on breast cancer survivors and the other on patients who already accessed healthcare at the largest hospital in Uganda. Understanding these downstaging practices and breast health messaging preferences in the general population would better inform interventions.

Prior to this study, little was known about the variation in downstaging practices and breast health messaging preferences across socio-demographic, healthcare access and prior breast cancer exposure factors in the country. In Uganda, healthcare access factors, such as where a woman receives her routine medical care and how medical care is usually paid for, are influenced by socio-demographic variables, including geographic region (rural vs. urban), education, and income.[14,32-34] While prior breast cancer exposure (positive family history and breast cancer education) could influence downstaging practices,[35-38] this question had not been evaluated.

Our study confirms that downstaging practices and breast health messaging preferences vary by socio-demographic, healthcare access, and prior breast cancer exposure factors. We found that few Ugandan women participate in downstaging practices (BSE: 27%, CBE: 15%), despite what previous research suggests (BSE: 60%, CBE: 40%).[30] These differences may be related to our community-based sample compared to the sample used by Elsie, *et al* that had already accessed the healthcare system. Within our sample, we similarly noted that women who received their healthcare at a health clinic, and therefore accessed the healthcare system, were twice as likely to have a recent CBE. While 54% of our sample reported receiving prior breast cancer education and did not participate in downstaging practices, we simultaneously observed that women who received previous breast cancer education were twice as likely to have

performed a BSE and over five times more likely to have had a CBE than women who had not received breast cancer education. Such findings provide some support on the positive impacts of breast cancer education by advocacy groups for improving practices in LMICs.[12,39] These findings also emphasize the challenges facing downstaging efforts in LMICs and suggest that some barriers are not being addressed with current education efforts.

As our second objective, we wanted to identify sources of information most likely to be effective at communicating breast health information. In our sample, we found that 66% of women prefer breast health messaging from their health provider. These findings support previous studies showing the patient-provider relationship as the most important influence on health practices in Uganda.[40,41] We also found that receiving breast cancer education significantly increased preference for breast health messages from their provider. These findings suggest that education targeting providers may boost current efforts led by village health teams and non-governmental organizations.

While an improvement on prior survey studies, the convenience-based sampling used here may also limit the generalizability of this study. Specifically, the urban and rural centers surveyed were mostly poor and their residents had less than a primary school education. While the middle class in Sub-Saharan Africa is growing, >67% of Ugandans are poor or vulnerable to poverty and have little education.[15,32] Thus, we believe that our study population provides a reasonable estimate of most Ugandan women. We also acknowledge that other social factors and beliefs beyond those considered here may adversely affect the stage of diagnosis, e.g., the role of traditional healers in delaying presentation to the hospital. While this goes beyond the scope of the current analysis, these other factors also warrant investigation, especially once standard early detection and diagnosis systems are well-established and functioning.

In summary, we conclude that knowledge of the variations in downstaging practices and breast health messaging preferences across different socio-demographic, healthcare access, and

prior breast cancer exposure factors can help inform future basic interventions. Our findings suggest that providing education to both health providers and women will improve downstaging practices, and this combined approach may be more effective in encouraging women to present early after self-detecting a lump.

Table 1. Overall sample characteristics

Variable	Total (n=401)
Socio-demographic factors	N (%)
Geographic region	
Urban	100 (25%)
Rural	301 (75%)
Age	
25-39	215 (54%)
40-49	107 (27%)
50-74	77 (19%)
Ethnicity	
Bantu	355 (88)
Other	42 (11)
Religion	
Christian	336 (84%)
Other	65 (16%)
Intimate Partner Status	
Married/Living with Partner	247 (62%)
Other	148 (37%)
Education	
≤Primary	265 (66%)
>Primary	116 (29%)
Income	
≤500,000 Shillings	150 (50%)
>500,000 Shillings	147 (50%)
Healthcare Access Factors	
Regular Source of Care	
Health Center	245 (61%)
Other (e.g. Self-care at home, traditional healer)	151 (38%)
Usual form of payment for care	
Self-pay	267 (67%)
Charity Care	102 (25%)
Other	32 (8%)
Prior Breast Cancer Exposure	
Family history of breast cancer	
Yes	52 (14%)
No	327 (86%)
Received breast cancer education	
Yes	181 (47%)
No	204 (53%)

Table 2. Downstaging practices and breast health messaging preferences

	N (%)
Downstaging Practices	
Performed Self Breast Exam	
Ever	103 (27%)
Never	284 (73%)
Clinical Breast Exam ≤ 12 months	
Yes	61 (15%)
No	335 (84%)
Breast Health Messaging Preferences[a]	
Who would most influence you to present early for CBE[b]	
Health Provider	261 (66%)
Family/Friend	92 (23%)
Societal	45 (11%)
If needed, where would you choose to go for a CBE?	
Local Health Clinic	130 (12%)
Regional Referral Hospital	115 (51%)
Other	151 (26%)

CBE: clinical breast examination

[a] Breast health messaging preferences to present early for a CBE in the theoretical scenario of self-detecting a palpable lump

[b] In the theoretical scenario of self-detecting a palpable lump

Table 3: Variation in breast cancer downstaging practices

	Downstaging Practices			
	Performed Self Breast Exam	P Value	Received CBE ≤ 12 months	P Value
Socio-demographic Factors				
Geographic region				
Urban	46%		34%	
Rural	20%	<.001	9%	<.001
Education				
≤Primary	21%		14%	
>Primary	39%	<.001	19%	.122
Healthcare Access Factors				
Regular Source Of Care				
Health Center	27%		20%	
Other (e.g. Self-care at home, traditional healer)	27%	.540	9%	.004
Prior Breast Cancer Exposure Factors				
Received Breast Cancer Education				
Yes	37%		27%	
No	18%	<.001	5%	<.001

Table 4: Variations In Breast Health Messaging Preferences

	Who would most influence you to present early for a CBE[a]			
	Health Provider	Family/Friend	Societal	P value
Socio-demographic Factors				
Geographic Region				
Urban	56%	20%	24%	
Rural	69%	24%	7%	<.001
Healthcare Access Factors				
Regular Source Of Care				
Health Center	72%	13%	15%	
Other	57%	32%	11%	.005
Usual Form Of Payment For Care				
Self-pay	62%	28%	10%	
Charity Care	71%	16%	13%	
Other	75%	9%	16%	.048
Prior Breast Cancer Exposure Factors				
Received Breast Cancer Education				
Yes	58%	30%	12%	
No	70%	18%	12%	.021

CBE: Clinical breast examination

[a] In the theoretical scenario of self-detecting a lump

Chapter 2

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 questions was conducted on a community sample of Ugandan women to assess their beliefs about breast cancer. Linear regression was used to ascertain associations between three categories of beliefs (culturally-perceived risks, scientifically-established risks, perceived benefits of early detection) and demographic factors potentially associated with early detection, including socio-economic factors, healthcare 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. Culturally-perceived risks of breast cancer were common (58.5-97.7%) and were described by the majority as the most important causes of breast cancer (69.2%), compared to scientifically-established risks (45.6-64.5%; 16.2%, respectively). Perceived benefits of early detection varied widely (12.3-70.3%) while many women held fatalistic attitudes towards their own detection efforts, including the common belief that cure is impossible once they could self-detect a lump (56.3%). Only having a lower income was associated with all breast cancer belief categories.

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 towards their own detection efforts will continue to be deleterious to breast cancer early detection in sub-Saharan countries like Uganda.

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),[3,21] which is associated with greater social stigma, more expensive treatment, and poorer survival.[22,42] 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.[19,23]

We previously showed a minority of Uganda women participate in breast cancer downstaging practices, despite receiving breast cancer education.[43] The Breast Health Global Initiative (BHGI), an organization focused on providing resource-stratified guidelines to improve survival in LMICs,[9] recommends understanding local beliefs about breast cancer as a prerequisite for successful, effective early breast cancer detection programs.[42] Indeed, beliefs help guide health behavior, but can be problematic when they are not grounded in scientific evidence and obstruct health-seeking behavior. Current efforts promoting breast cancer awareness in Uganda occur through television or radio commercials and health fairs run by village health teams (VHTs). VHTs are elected volunteers from their communities that are taught health information from a clinical provider at the community health centers to deliver to their villages.[44] 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). Misunderstanding the implications of beliefs may help explain why current education efforts, while reaching approximately 50% of the population, have failed to change health behavior or reduce late-stage presentation in Uganda.[43]

Few studies have sought to understand breast cancer beliefs in Uganda.[30,31] Notably, existing studies did not differentiate types of beliefs nor did they assess which beliefs about breast cancer were most important to Ugandan women. General breast cancer beliefs can be categorized into culturally-perceived risks, scientifically-established risks and perceived benefits of early detection. Studying these categories of beliefs separately is important because they have unique implications for what interventions may be most effective and may identify beliefs held by Ugandan women that need addressing in education efforts to reduce late-stage presentation. For example, a woman may ignore a growing painless breast mass if they lack the culturally-perceived risk for developing breast cancer until they learn of their scientifically-established risks. Similarly, women with fatalistic attitudes towards breast cancer (i.e. do not perceive a benefit of early detection) may not see the benefit of spending family resources to seek care after self detecting a breast lump until they understand the relationship between early detection and survival.

Previous work also did not study associations between breast cancer beliefs and demographic factors potentially associated with early detection, including socio-economic factors, healthcare access, prior breast cancer knowledge, and personal detection practices. Such associations are requisite to identify health disparities among at-risk subpopulations and develop subgroup-specific interventions. While not studied in the context of beliefs, socio-economic factors, healthcare access, prior breast cancer knowledge, and personal detection practices determine when and how sub-Saharan women seek medical care.[31,45-47] Studies in other sub-Saharan African countries show that these factors are associated with breast cancer beliefs,[45,48,49] possibly because women with certain socio-economic factors, healthcare access, prior breast cancer exposure, and personal detection practices may be disproportionately targeted for educational outreach.

For example, women of a particular religious faith may be disproportionately targeted or receptive to breast health information from foreigners of similar faiths. Identifying subpopulations of women most likely to hold beliefs about breast cancer will help inform efforts by the Ugandan Ministry of Health to improve breast cancer awareness.

To address these gaps in the literature and design useful education, we identify breast cancer beliefs and assess their frequency in a large community sample of Ugandan women. We also test associations between breast cancer beliefs and socio-economic factors, healthcare access, prior breast cancer knowledge, and personal detection practices. These data will provide essential information to design 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 fundraiser activities for breast cancer control. UWOCASO helped select the study geographic areas based on population density.[50] 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/square mile), and from the villages and communities in South Central Uganda (population density range = 1-500 people/square mile).[13]

Data Collection

UWOCASO, assisted by local community leaders, recruited women ≥25 years with no personal history of breast cancer. Trained UWOCASO volunteers interviewed participants individually in a semi-private area. Participating women were given 10 U.S. dollars to complete a 30-minute survey.

This study was exempted from full IRB review because it extracted data from anonymous surveys.

Measures

The creation and validation of the Attitudes on Breast Cancer Surveillance and Knowledge (ASK) survey has been described previously.[50] Briefly, we used standard methods of cross-cultural adaptation and development of surveys.[51-60] We reviewed previously published data from a qualitative study of 18 Ugandan breast cancer survivors,[31] a mixed quantitative-qualitative study of 100 women presenting to the Ugandan national referral hospital,[30] and three focus groups of 6-8 women. From these data, we selected constructs relevant to beliefs about culturally-perceived risks, scientifically-established risks, and perceived benefits of early detection. Our team and local experts then developed a survey. It included translating from English (primary language) and Luganda (common local language) as well as pilot testing.

Belief categories. From the constructs identified during the survey development, we created three separate belief categories: six items for culturally-perceived risks, three items for scientifically-established risks, and five items for perceived benefits of early detection. For all 14 items, individuals could answer statements using response options: Disagree, Unsure, and Agree. For our analysis, we combined the "Unsure" responses with the incorrect response (either agree or disagree depending on the item) to

differentiate between correct responses and either incorrect or uncertain responses. Women also were asked to list the three most common causes of breast cancer (free response).

Socio-economic factors. Socio-economic variables included age (continuous variable), geographic region (urban, rural), ethnicity (Bantu, other), religion (Christian, other), intimate partner status (married/living with partner, other), education (≤ Primary, >Primary) and income (≤ 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.

Healthcare access. Healthcare factors included where women received most of their healthcare (Community Health Center, Regional or Referral Hospital, Self-care at Home, Other) and how they usually paid for this care (Self pay, Government/Subsidized, Other). Women reporting more than one method for their healthcare payment were place in the other category.

Prior breast cancer knowledge. Women 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. Women reported their lifetime history of examining or observing their own breasts (BSE) for palpable lumps (ever, never) and if they had undergone a CBE 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 using the DatStat Illume software package (Seattle, WA). We produced descriptive information for each item and then created

summary scores for each breast cancer belief category by summing the correct responses and dividing by the total items in that category. We used linear regression to ascertain associations between responses for the three categories of beliefs (culturally-perceived risk, scientifically-established risks, and perceived benefits of early detection) and the socio-economic factors, healthcare access, prior breast cancer knowledge, and personal detection practices. A p-value <.05 was considered significant. All statistical analyses were performed with IBM SPSS (Chicago, SPSS Inc.).

Results

A total of 401 participants participated in this survey, 100 from the capital city and largest metropolitan area in Uganda (Kampala) and 301 from rural villages and communities in South Central Uganda (Rakai district). Table 1 summarizes the characteristics of the surveyed population. The mean age of the women was 40.7 years. Most women were Bantu (89.4%), Christian (83.8%), married or living with a partner (62.5%), and had a primary education or less (66.3%). In terms of health care, women were distributed evenly between self-care at home (29.0%), community health center (32.8%), and regional/referral hospital (29.0%). Most women (53.1%) self-paid for their healthcare. The majority of women had no family history of breast cancer (86.3%) and had not received prior breast cancer education (53.0%). Most women had never examined their own breasts for lumps (73.4%) and had not received a CBE in the previous 12 months (84.6%).

Frequency of Breast Cancer Beliefs

Table 2 depicts information regarding the beliefs about breast cancer culturally-perceived risks, scientifically-established risks, and perceived benefits of early detection.

Overall, the frequency for culturally-perceived risks showed very little variability with 82.6 to 97.7% supporting such beliefs as trauma causing breast cancer, carrying items in a bra causing breast cancer, and not taking care of oneself causing breast cancer. Many women exhibited low beliefs in scientifically-established risks (45.6 to 64.5%). Most women believed that early detection and being checked regularly for breast cancer would result in a cure if breast cancer were detected (79.9% and 87.7%, respectively), but simultaneously thought that most breast lumps represented cancer and that breast cancer detected as a lump was too late to cure (70.3% and 56.3, respectively).

Most important perceived causes of breast cancer

Table 3 depicts the frequency of the three most important culturally-perceived risks of breast cancer (women's perspective). Almost half of women surveyed (46.7%) believed that wearing used bras or sharing bras and carrying items in bras caused breast cancer. A smaller percent of women believed that scientifically known risk factors (16.7%), infection (10.3%), environmental exposures (8.1%), and trauma (4.1%) caused breast cancer.

Variation in Breast Cancer Beliefs by Socio-economic Factors, Healthcare Access, Prior Breast Cancer knowledge, and Personal Detection Practices

We consequently calculated summary scores for each breast cancer belief category and coded them such that higher mean scores indicate more accurate beliefs about culturally-perceived risks, scientifically-established risks, and perceived benefits of early detection. The ranges of mean scores in the women surveyed for beliefs in culturally-perceived risks, scientifically-established risks, and perceived benefits of early detection were .00-0.67, 0-1.00, and 0-1.00, respectively. This means that while some

women were 100% correct with regard to scientifically-established risks (n = 34) and perceived benefits of early detection (n = 30), the highest proportion of correct answers with regard to culturally-perceived risks was 67% (n = 4).

Using bivariate linear regression models, we analyzed socio-economic factors, healthcare access, prior breast cancer knowledge, and personal detection practices for predictors of culturally-perceived risks, scientifically-established risks, perceived benefits of early detection (Table 4). Culturally-perceived risks were associated with age, education, income, and regular source of care. Scientifically-established risks were associated with religion, income, usual form of payment for healthcare, family history of breast cancer, and performed BSE. Perceived benefits of early detection were associated with education and income.

Finally, we conducted 3 separate multivariable linear regression models with those variables that were significant predictors in bivariate regressions. Culturally-perceived risks remained significantly associated with age (p = .043), income (p =.013), and regular source of care (other vs. self; p = .009). The relationship between education and beliefs in culturally-perceived risks was no longer statistically significant (p = .063). Scientifically-established risks remained significantly associated with religion (p = .04), income (p = .009), and usual source of payment for healthcare (government vs. self; p = .04). Associations with performing a BSE and family history were no longer significant (p = .088-.150). Perceived benefits of early detection were significantly associated with income (p = .001), but not with education (p = .389).

Discussion

In this study, we assess Ugandan women's beliefs about culturally-perceived risks, scientifically-established risks, perceived benefits of early detection to help

understand the average two-year delay in seeking medical care after self-detecting a breast lump. Understanding the beliefs will help inform educational interventions designed to reduce late-stage diagnosis. We found widespread beliefs in culturally-perceived risks; these beliefs were largely independent of socio-econominc factors, healthcare access, prior breast cancer knowledge, and personal detection practices. We also found few women believed in scientifically-established risks and many perceived little benefits in early detection. In addition, receiving previous breast cancer education was not associated with a significant decrease in culturally-perceived risks or increase in scientifically-established risks and perceived benefits of early detection, suggesting that current breast cancer education efforts are inadequate.

Beliefs in culturally-perceived risks emerged as particularly important to address in future interventions to increase breast cancer awareness. It is notable that no woman in our sample correctly rejected all culturally-perceived risks. Further, older women, poorer women, and women preferring self-care (relative to women with other types of regular source of care), were particularly at risk for believing in culturally-perceived risks. Similar to a previous study, we specifically found carrying items in bras, using steel brushes to clean pots, and breast trauma were commonly held etiologic beliefs about breast cancer in Uganda.[31] These beliefs in culturally-perceived risks relate 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 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 dispel culturally-perceived risks and increase awareness on scientifically-established risks

associated with Westernization, such as early menarche, late menopause, parity, and obesity.[61] These findings also support involving local non-Western stakeholders in breast cancer awareness efforts to promote scientifically-established risks and dispel beliefs in culturally-perceived risks around contracting breast cancer from Westerners or Western items.

The prevalence of beliefs in scientifically-established risks was low. Women who were poor, Christians, paid for healthcare through government/subsidization, and who performed a BSE showed significantly more accurate beliefs in scientifically-established risks. These findings may suggest that the poor or those of Christian religions may be disproportionately targeted or receptive to breast health education as currently delivered or receiving their subsidized care at health centers with religious affiliations.[62-64] The association between more accurate knowledge and performing BSE supports the use of BSE as a marker of a higher level of breast health awareness, as it suggests that the information has been understood and behavior has changed.[43] It also should be noted that in our overall sample, breast health education was not associated with increased beliefs in scientifically-established risks. The currently ineffective breast education curriculum supports the necessity for a change in message or delivery of educational efforts.

An essential component of raising breast cancer awareness includes believing that breast cancer is survivable and that early detection increases chances of survival. There was wider variation with regard to the perceived benefits of early detection relative to beliefs in culturally-perceived risks and scientifically-established risks. Specifically, we found that most women believed that early detection saves lives; however, they simultaneously believed that most breast lumps represent breast cancer and that a self-detectable breast lump meant that cure was unlikely. Women who were poor, interestingly, showed more accurate knowledge about early detection beliefs, potentially

due to the disproportionate targeting described above. Previous studies have shown that this fatalism in one's own detection efforts can prevent or delay women from seeking care after self-detecting symptoms.[65,66] These beliefs may help explain why women wait an average of two years after self-detecting a breast lump before seeking medical care.[67] 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 breast cancer survivors in future breast cancer awareness efforts.

Many of our survey questions have successfully been used in other cultures to identify breast cancer beliefs. However, the application/results of surveys are limited by cultural context. For example, several women listed 'inherited/genetics' as a scientifically-established risk; however, in deeper discussions, the subjects said they really believed they could inherit breast cancer as a curse from an enemy. Similarly, many women believed that trauma caused breast cancer; yet women who elaborated on the trauma specifically referenced domestic violence. These beliefs in culturally-perceived risks makes it easier to understand the social stigma influencing a woman's decision not to talk about having breast lumps or seek medical care. The cultural subtleties show the importance of collaborating with cultural experts, such as the UWOCASO women who collaborated on this study. Future breast cancer awareness should involve these cultural experts to target common beliefs and misconceptions about breast cancer in order 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 lived. Since most Ugandans are poor or vulnerable to poverty and have

little education,[15,32] we believe our study population provides a reasonable estimate of the beliefs held by most Ugandan women. Further, while this study may have been limited by specific questions to assess beliefs about culturally-perceived risks, scientifically-established risks, perceived benefits of early detection, and thus may have omitted some other beliefs, we derived the beliefs used in this study from focus groups of breast cancer survivors throughout Uganda and supplemented yes/no questions with free response ones. We also identified few additional beliefs (3.2%) in our free response questions not covered in our closed-ended questions. Thus, we believe we accurately assessed the beliefs of Ugandan women as best possible.

In summary, we have assessed the beliefs about culturally-perceived risks, scientifically-established risks, perceived benefits of early detection among Ugandan women. We show that despite receiving previous breast cancer education, most women still held beliefs that may prevent them from seeking care early after self-detecting a lump, most notably fatalism toward women's own self detection efforts. This information can be used to improve breast cancer education as part of an early breast cancer detection program.

Table 1: Population Characteristics (n = 401)

Socio-economic Factors	**Mean (SD)**
Age	40.7 (9.9)
	N (%)
Geographic Location	
Urban	100 (24.9)
Rural	301 (75.1)
Ethnicity	
Bantu	355 (89.4)
Other	42 (10.6)
Religious Group	
Christian	336 (83.8)
Other	65 (16.2)
Intimate Partner Status	
Married/Living with Partner	247 (62.5)
Other	148 (37.5)
Education	
≤Primary	265 (66.3)
>Primary	135 (33.8)
Income	
≤ 500,000 Shillings	150 (50.5)
>500,000 Shillings	147 (49.5)
Healthcare Access Factors	
Regular Source of Care	
Self-care at Home	115 (29.0)
Regional/Referral Hospital	115 (29.0)
Community Health Center	130 (32.8)
Other	36 (9.1)
Usual Form of Payment for Care	
Self Pay	213 (53.1)
Government/Subsidized	96 (23.9)
Other	92 (22.9)
Prior Breast Cancer Knowledge	
Family History of Breast Cancer	
Yes	52 (13.7)
No	327 (86.3)
Received Breast Cancer Education	
Yes	181 (47.0)
No	204 (53.0)
Personal Detection Practices	
Performed Self Breast Exam	
Ever	103 (26.6)
Never	284 (73.4)
Clinical Breast Exam ≤ 12 months	
Yes	61 (15.4)
No	335 (84.6)

Table 2: Frequency of Incorrect Breast Cancer Beliefs

Beliefs (Correct Answer)	Number Incorrect (%)
Culturally-perceived Risks	
A hard blow may cause cancer. (False)	348 (86.8)
Carrying money in the bra can cause cancer. (False)	389 (97.5)
Carrying a cell phone in the bra can cause breast cancer. (False)	389 (97.7)
Sharing bras may cause breast cancer. (False)	379 (95.2)
Cancer can be caused by not taking care of one's self. (False)	328 (82.6)
It seems like everything causes breast cancer. (False)	231 (58.5)
Scientific-established Risks	
Being overweight increases the risk of developing breast cancer (True)	218 (54.9)
Having your first child after 30 years old increases your risk of breast cancer. (True)	256 (64.5)
Breast cancer can occur in women younger than 40 years old. (True)	216 (45.6)
Perceived Benefits of Early Detection	
Most breast lumps are cancerous. (False)	277 (70.3)
For many women, breast cancer can be successfully treated. (True)	153 (38.6)
By the time a woman can feel a breast lump, it is too late to cure. (False)	219 (56.3)
Getting checked regularly for breast cancer can help find cancer when it's easy to treat. (True)	49 (12.3)
Breast cancer is an illness that when detected early can usually be cured. (True)	80 (20.1)

Table 3: Most Important Perceived Cause of Breast Cancer

Cause	N (%)
Culturally-perceived Risks	539 (69.2)
Wearing Used Bras or Carrying Items in Bras	363 (46.7)
Infection	80 (10.3)
Environmental Exposure	63 (8.1)
Trauma	33 (4.1)
Scientifically-established Risks	130 (16.7)
Unknown	52 (6.7)
Other	25 (3.2)

Table 4: Predictors For Breast Cancer Beliefs

Characteristic	*Culturally-perceived Risks*[1]		*Scientific-established Risks*[2]		*Perceived Benefits of Early Detection* [3]	
	Mean (SD)	**P-value**	**Mean (SD)**	**P-value**	**Mean (SD)**	**P-value**
Socio-economic						
Age						
<45 years old	.148 (.149)	**.017**	.424 (.296)	.799	.620 (.239)	.109
≥45 years old	.109 (.134)		.415 (.311)		.574 (.293)	
Geographic Location						
Urban	.135 (.164)	.996	451 (.313)	.259	.598 (.257)	.728
Rural	.135 (.139)		.412 (.297)		.609 (.256)	
Ethnicity						
Bantu	.136 (.147)	.764	.417 (.302)	.417	.607 (.253)	.606
Other	.128 (.124)		.458 (.299)		.585 (.281)	
Religious Group						
Christian	.134 (.146)	.646	.437 (.299)	**.024**	.612 (.250)	.293
Other	.143 (.143)		.344 (.422)		.575 (.283)	
Intimate Partner Status						
Married/Living with Partner	.139 (.147)	.567	.422 (.299)	.955	.612 (.241)	.456
Other	.131 (.143)		.420 (.303)		.592 (.283)	
Education						
≤Primary	.116 (.133)	**<0.001**	.413 (.302)	.476	.587 (.259)	**.050**
>Primary	.173 (.161)		.436 (.302)		.651 (.249)	

Income						
≤ 500,000 Shillings	.120 (.131)	**.009**	.480 (.295)	**.005**	.664 (.223)	**.002**
> 500,000 Shillings	.164 (.151)		.382 (.299)		.471 (.260)	
Healthcare Access						
Regular Source of Care						
Self-care at home	.121 (.135)	REF	.422 (.330)	REF	.590 (.281)	REF
Regional/Referral Hospital	.120 (.133)	.993	.408 (.294)	.809	.625 (.237)	.307
Community Health Center	.148 (.151)	.139	.440 (.293)	.568	.598 (.254)	.798
Other	.186 (.180)	**.020**	.266 (.423)	.853	.628 (.249)	.438
Usual Form of Payment for Care						
Self-pay	.135 (.144)	REF	.398 (.301)	REF	.609 (.246)	REF
Government/Subsidized	.138 (.156)	.841	.488 (.283)	**.016**	.608 (.263)	.986
Other	.133 (.138)	.927	.407 (.313)	.815	.595 (.274)	.682
Prior Breast Cancer Knowledge						
Family History of Breast Cancer						
Yes	.140 (.138)	.650	.497 (.298)	**.046**	.603 (.251)	.634
No	.130 (.142)		.405 (.299)		.584 (.285)	
Received Breast Cancer Education						
Yes	.140 (.153)	.449	.441 (.314)	.352	.630 (.245)	.053
No	.128 (.137)		.412 (.289)		.578 (.265)	
Personal Detection Practices						
Performed Self Breast Exam						

Ever	.132 (.153)	.904	.473 (.318)	**.025**	.642 (.242)	.059
Never	.134 (.143)		.395 (.291)		.585 (.260)	
Clinical Breast Exam ≤ 12 months						
Yes	.133 (.483)	.910	.483 (.291)	.095	.628 (.237)	.487
No	.135 (.145)		.413 (.303)		.603 (.258)	

[1]For *Culturally-perceived Risks*, the range of the means was .823 - .885, with a higher mean indicating a higher number of correct responses to etiologic beliefs questions.
[2]For *Scientific-established Risks*, the range of the means was .344 - .488, with a higher mean indicating a higher number of correct responses to risk questions.
[3]For *Perceived Benefits of Early Detection*, the range of the means was .571 - .664, with a higher mean indicating a higher number of correct breast cancer detection belief questions.

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