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Experiences and perceptions regarding clinical breast exam screening by trained laywomen in Malawi

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Abstract

Purpose—Despite the increasing burden, breast cancer control in sub-Saharan Africa is insufficient. Late diagnosis and lack of early detection and screening services contribute to high mortality. Clinical breast exam (CBE) screening can be valuable in low-income countries, including use of community health workers and non-health professionals to conduct exams. We

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Compliance with ethical standards

Disclosure of potential conflicts of interest

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Human Subjects Research

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The National Health Services Research Committee and authors' institutional review board approved this study.

Informed consent

All participants provided written informed consent prior to the screening study. Additional verbal consent was obtained before conducting the interviews.

assessed experiences of women who underwent CBE screening by trained laywomen in Lilongwe, Malawi, as part of a pilot program.

Methods—The pilot study invited women attending urban health clinics to a breast cancer educational talk followed by CBE screening by trained laywomen. We purposively sampled participants from the pilot study and interviewed them about the screening experience and future cancer education programs and services.

Results—Overall participants had positive experiences and were willing to undergo CBE screening by trained laywomen. Participants were motivated by the educational talk, shared newly acquired cancer knowledge with their social networks, and encouraged others to seek screening. Screened women suggested strategies for future interventions including combining breast and cervical cancer screening, using female providers, partnering with community leaders to increase uptake, and expanding services into the community.

Conclusions—Asymptomatic Malawian women accepted CBE screening by trained laywomen and considered breast cancer an important health issue. Women appreciated combined education and screening services and proposed further linkage of breast and cervical cancer screening. Based on our results, training laywomen to educate the public on breast cancer and conduct CBE is a feasible breast cancer control strategy in sub-Saharan Africa.

Keywords

breast cancer screening; Malawi; sub-Saharan Africa; education; qualitative interviews

Introduction

Breast cancer is the most common female cancer worldwide. In sub-Saharan Africa (SSA), disease burden is high, and survival rates are low [1, 2]. Lack of awareness, misconceptions about the disease, and few screening and early detection services contribute to advanced diagnoses and poor outcomes [3].

In Malawi, breast cancer patients are often diagnosed with large tumors more than a year after symptoms initially present [4]. Women face multiple individual, interpersonal, cultural, and system-level barriers which affect access to care and delay diagnosis [5]. Despite being a documented screening priority in Malawi's national health plan, coordinated screening and targeted early detection efforts for breast cancer do not exist [6]. Mammography is not widely available, and although regular clinical breast exam (CBE) is recommended, it is not routinely performed.

Because CBE may be pragmatic and cost-effective for low-resource settings like Malawi [3, 7], we conducted a pilot study evaluating feasibility and acceptability of CBE screening performed by laywomen [8]. We found that laywomen could be successfully trained to provide breast cancer education and competently perform CBE [9]. We also demonstrated 82% acceptance of CBE screening among women attending urban health clinics, suggesting feasibility of this approach in our context [10].

The objective of the current study was to explore perceptions and experiences of Malawian women who underwent a CBE, to qualitatively assess our intervention, and to inform scale-up and design of future breast cancer programs, including integrating CBE into existing services such as cervical cancer screening.

Methods

Pilot CBE Screening Study

Four laywomen, or “Breast Health Workers” (BHWs), were trained to deliver breast cancer educational talks and conduct CBE. Screening was implemented in five urban clinics in Lilongwe. For the pilot study, women aged 30 years or older, with no prior breast cancer or breast surgery, and clinic attendance for reasons other than a breast concern were eligible. Women with abnormal CBE were referred to a study physician. All palpable masses confirmed by physician exam were pathologically assessed. Additionally, randomly selected women with normal CBE underwent either breast ultrasound by radiology or CBE performed by study physician to evaluate CBE accuracy.

Qualitative Data Collection

For this qualitative study, we purposively recruited participants based on exam outcome, age, and exposure to the educational talks. Informed consent was obtained before conducting the interviews, which took place after the screening study ended. Interviews lasted approximately 30 minutes. We developed a semi-structured interview guide to solicit feedback about the educational talk and CBE experience. Topics included perceptions, attitudes, and satisfaction regarding the talk, CBE experience, ultrasound and referral process, interaction with BHWs, and optimal design of future services, including the possibility of bundling breast and cervical cancer screening. BHWs were trained on social science interviewing and carried out all data collection; BHWs interviewed participants from sites where they did not facilitate talks or conduct CBE. Immediately following each interview, notes and key responses were summarized. Probing questions were modified iteratively as initial findings were interpreted with the field time (BHWs, REK, and LG). Data collection continued until thematic saturation was reached. Interview recordings were transcribed verbatim in Chichewa by the interviewers and translated into English. A subset of transcripts was back-translated to check accuracy.

Data Analysis

All transcripts and summaries were read multiple times by three authors (REK, ARM, and LG) and BHWs provided initial interpretation of the findings. Transcripts were organized and coded in Atlas.ti using constant comparison and thematic analysis to understand women’s experiences [11, 12]. A codebook based on the interview guide categories and sub-categories was applied to a subset of transcripts by the primary coder (ARM). After discussion with the secondary coder (REK) the codebook was revised and applied to the full dataset. The secondary coder applied the codebook to 20% (n=5) of transcripts to compare coding. The two coders independently reviewed coded text and cooperatively analyzed patterns to identify meaningful themes, compare across subgroups, and interpret findings.

Results

Sample Characteristics

One thousand women were enrolled and screened in the pilot study; 67 (7%) had abnormal CBE and were referred for physician exam. We approached 30 women from the pilot study to participate in the follow-up interviews, and 25 agreed to participate (83%). The interviews took place 1.3 to 5 months (median 3.25) after screening. The median age was 40 years (range: 31–61), and most were married with some secondary education living in urban areas (Table 1). Regarding socioeconomic position, many had electricity at homes. Among women interviewed, seven with normal CBE results were randomized to receive an ultrasound, but only five attended.

Perceptions about the educational talk

We recruited ten participants who attended educational talks at various recruiting health centers. These women gave very positive feedback about the talk, saying they enjoyed the session and thought that learning about their health and bodies was important. For many it was the first time they heard about breast cancer in a formal setting:

“The talk was very good because it was my first time to hear things like that. We would just hear that so and so has breast cancer and that they have removed the breast, but never heard about the signs of cancer.”

When asked to recall what they learned, nearly all women correctly identified at least one sign/symptom and a few could name risk factors. Importantly, they retained knowledge opposing commonly held myths: they remembered that keeping cell phones and money in a bra does not cause cancer. Others discussed the importance of early detection, “the dangers” of being diagnosed late, and that cancer is curable at early stages. Women indicated that the flipchart with pictures of signs/symptoms used during the talk was helpful: “it was explaining well even for a person who doesn’t know how to read, you can just point on the flipchart and she can know what cancer is.”

Many women reported sharing what they learned during the talk with others, including neighbors, female and male co-workers, women’s community groups, church groups, relatives, and husbands. They shared information about the screening exam, benefits of early detection, and emphasized that women should “rush to the hospital” if they have signs. Some reported telling others how to do a breast exam, though instruction on self-exams was not covered in the educational talk. Women indicated that they felt compelled to tell others because breast cancer is a “dangerous disease”:

“It is a very important message, and this cancer is increasing and a lot of people are being found with it. And what hurts most here in Malawi is that when someone has been found with cancer, it is found at a later stage, the time when this person can’t even have an operation, so I saw it helpful for people to know how they can realize fast that it is cancer so that maybe they can receive treatment early before it starts spreading to different places.”

Learning about breast cancer during the talk also motivated women to participate in screening. One woman who knew someone who died of breast cancer participated in screening because previously she had “never heard of the place where you can go for breast cancer examination and be helped.” Knowing or seeing a woman without a breast was mentioned by 9 women as a motivating factor and increased women’s perceived disease severity.

Experiences of screening exam

All 24 participants who underwent CBE had positive experiences. Many were grateful to have access to screening, and a couple of women noted that it was “my lucky day” to receive an extra service they had not anticipated when attending clinic. Although three women indicated they were afraid before and/or during the exam, they felt relieved after having a normal result. When questioned about sensations like pain, only one woman who was found to have a small nodule indicated that the exam was painful. Thirteen women underwent screening because they believed they would be helped if they had an abnormality; they were confident in the health system to provide the treatment they needed if something abnormal was discovered through screening.

“I was happy that I had my breasts screened and it is good to be examined to know how I am [...]even if they find that I have a problem they will help me; if they find that I have nothing it’s also a good thing.”

Because exams were conducted in private rooms by female BHWs, participants did not feel embarrassed to undress; one-third said they would be less comfortable if a man had performed the exam. Participants noted the thoroughness of the exam, which made them confident in the results. A few women raised concerns and asked questions during the exam; they were glad the BHW addressed questions, which was perceived as high quality care compared to other health care encounters. Participants felt well-prepared and liked how the BHW explained what she was doing throughout the exam. Because of these explanations, even a few women who did not attend the educational talk cited new breast cancer knowledge. Although six women expressed satisfaction about learning to do self breast exam, this was not the intent of the study.

Perceptions about providers

In general, participants appreciated BHWs’ welcoming disposition and indicated that they had good bedside manners. Women felt comfortable with BHWs and said they were encouraging and non-judgmental during the exam. Whereas one participant felt a doctor should have done the exam, all others believed any trained person was acceptable. In fact, some women thought doctors were too busy taking care of sick patients and preferred having someone else perform CBE: “It’s better to have a trained person who is not a clinician because people are always more open to explain everything.”

Most (two-thirds) of participants indicated that they would not have a problem with a male provider, although most preferred to have a woman. Participants commented that “you can feel free” with a woman and that they might “feel shy” with a man. Though they often mentioned seeing men work in obstetric departments, some indicated that in these settings

women accept male providers because “you are in so much pain” compared to elective cancer screening where a woman would be more appropriate.

Perceptions of ultrasound

To evaluate the performance of BHW CBE, a subset of women with normal exams underwent breast ultrasound. Although a couple of women noted logistical barriers to completing the ultrasound referrals (e.g., inadequate radiology staff or long wait times), most women liked the ultrasound because it was “the last step” confirming they did not have cancer. They thought both screening modalities were helpful, and most believed ultrasound was more accurate, deeming it more “trustworthy” because it “examines all that is inside” compared to the “hands only” CBE:

“Just by touching your breast, you can’t know everything which is inside your breast. While having an ultrasound you can see other things in your breast [...] We cannot differentiate which lumps are cancerous or not. And having an ultrasound, they can differentiate the lumps.”

Two women trusted CBE more than ultrasound, noting that “machines are made up by men and can jam and lie sometimes.” They also pointed out that CBEs are more feasible for doing screening in the community “because it is simple, you can also walk long distances.”

Prioritizing health education with screening services

The participants believed it was important to educate women before offering screening so they could know more about the disease and make an informed decision. In general, they agreed that educational talks could “motivate women to go get screened.” Some felt a health talk alone was suboptimal, and believed services should also be made available, to prevent unnecessary worrying about perceived symptoms and to “know how my body is.”

Perceptions about bundled cancer screening programs

When asked about a combination of women’s cancer screening (i.e., offering CBE with visual inspection for cervical cancer), all women indicated it would be valuable and more efficient because “these things go together.” Saving time and money so they would not have to “be seen for one problem [...] and go back and then you go again” was highly desired. However, one woman who said she was not “ready” or willing to have cervical cancer screening agreed that the two services should be offered together, but that the patient should be able to decide if she wants both.

Participants had many suggestions for where a bundled program could take place, mainly that the “program goes everywhere,” that it should be widespread “for everyone to access this help.” Women suggested local health centers, village dispensaries, district hospitals, and tertiary hospitals as suitable facilities. In general, they thought any health facility that serves women would be appropriate, including family planning (FP), maternity, antenatal, and pediatric clinics. Two women recommended screening at locations beyond FP because not all women use FP services, and others suggested antenatal might not be the ideal audience for screening education. Most indicated as long as the provider was well-trained they would accept a doctor, nurse, or community volunteer; however, a few thought doctors should do

the bundled screening because “they know more” and two thought nurses were more trustworthy. Although some preferred “a fellow lady” perform the exam, in general male providers were acceptable.

We also asked which cancer screening they would prioritize, but no clear preference emerged. Women gave very similar reasons for preferring breast or cervical cancer screening (Table 2). However, the location of the cancer was a commonly cited deciding factor. In supporting cervical cancer screening, some women rationalized that breast symptoms are visible and can be examined by women themselves, whereas, the cervix is “inside, we don’t see it” and “you cannot do it yourself.”

Suggested strategies to improve breast cancer control

Most suggestions involved expanding services beyond the current study, such as making screening more widely available through additional hours and study continuation beyond the pre-specified accrual target. Some women who required further work-up or were randomized to undergo ultrasound gave feedback on logistics, including decreasing wait times for follow-up appointments and having same-day ultrasounds.

Other general suggestions included making announcements at churches so more women would attend, having a stand-alone screening clinic so women would know exactly where to go, holding educational talks and screening in the same location, offering services in the community, and creating a uniform for BHWs. A couple of women who did not receive ultrasounds thought another method, “not just hands,” should be used for screening, and one woman thought there should be a blood test to diagnose breast cancer “like other illnesses.” Participants also suggested other ways to do education using radio and television programs, dramas, and songs, or distributing pamphlets. They recommended doing outreach at community venues, including churches, health care centers, schools, or village meetings and emphasized that men, especially pastors and chiefs, should also be involved.

Discussion

This qualitative study provides insights into participation by Malawian women in a CBE screening study utilizing trained laywomen and suggestions for future interventions. The women we interviewed were overwhelmingly positive about their CBE experience and enthusiastic about sharing the information they learned with others. They welcomed screening by laywomen and were appreciative of the opportunity to be screened for breast cancer. These findings highlight interest within Malawi in preventive services and underscore the importance of patient education combined with cancer services.

Our results suggest strategies for educating Malawian women about multiple types of cancers and services; we also found that education talks prompted screening participation. Our participants were interested in combined education with screening services and bundled breast and cervical screening. They emphasized the importance of reaching women in rural areas and working with local leaders to spread awareness. Women were able to recall targeted messages to dispel local misconceptions about causes of breast cancer, and correctly remembered signs/symptoms of the disease. Participants had high recall of the visual

graphics from the flip chart suggesting the importance of visual aids as key components in breast cancer education to enhance comprehension across all levels of education [13].

Although some studies have found that strong fatalistic beliefs and fears of being diagnosed deter screening and seeking care [14, 15], women in our study valued early detection. These findings are consistent with previous work in Malawi [16], and highlight the importance of integrating health beliefs into educational outreach and promoting curability through survivors. Participants understood the benefits of early detection and trusted the health system would provide adequate care to make screening worthwhile. Knowing or seeing a breast cancer survivor gave women hope that appropriate treatment was available. They were often motivated by their social experiences, to undergo screening and later used their social networks to spread breast cancer knowledge and encourage screening. Train-the-trainer and social network programs have been successfully used to promote health for other diseases in Malawi [17–19] and similar models for cancer may improve awareness and early detection [20].

The participants were grateful to receive screening, perceived the care they received as high in quality, and had positive experiences overall. The approachability of BHWs was a key factor to the success of this intervention, who despite being trained laywomen, were perceived as acceptable providers for CBE screening. Some of this acceptance may be due to the tendency for Malawians to respect health workers equally [16, 21]; for example, one participant noted they are “all the same, either trained health workers or doctors.” Additionally, Malawi employs a cadre of Health Surveillance Assistants who work in a range of urban and rural settings providing a broad spectrum of services. Thus, Malawians are accustomed to receiving care from trained people other than doctors and nurses. The interest and enthusiasm about breast cancer screening that we observed reflect an opportunity to promote preventive cancer services via this task shifting approach.

Similar to other studies, we identified several potential barriers to breast cancer screening. First, embarrassment and modesty have been noted as deterring factors of screening [22]. Our participants preferred female providers for cancer screening, which is consistent with previous research in Malawi [21]. Concepts of curative care, low awareness, and poor health seeking behaviors have been well documented as barriers to screening and early detection in other studies [3, 23]. Women in our study discussed negative local beliefs about preventive care including that it takes away doctors’ time from other patients with urgent needs, so many patients only seek care when they are very ill. For this reason, using laywomen for asymptomatic screening may be an acceptable approach to providing preventive care in Malawi. This is consistent with other African studies which effectively used peer volunteers or lay health workers for education [24].

Among women who experienced both a CBE and ultrasound in our study, most preferred the ultrasound if they could choose only one screening approach. Their rationale for this preference centered on the perception of the ultrasound being more accurate than physical exam. However, expansion of ultrasound into community settings in Malawi would be more difficult than CBE due to insufficient material and financial resources as well as strong lack of expertise in quality breast ultrasound. Moreover, the pilot study found CBE by trained

laywomen in Lilongwe to have excellent clinical performance compared to physician exam [10].

One concern from this qualitative study was that a handful of women believed they could do their own self-exam even though they were never formally instructed to do it. Moreover, although women should be familiar with their own bodies, self-exams have not been proven to be an effective screening tool [25]. CBE screening programs should consider explicitly advising patients that undergoing and experiencing CBE does not constitute adequate training in self-exam.

Limitations to this study must be noted. We specifically recruited women who received a CBE through our pilot implementation study, and experiences may therefore not be generalizable to other settings, such as small rural health centers and community settings. Our intervention was designed to integrate CBE screening within existing clinics, so participants were already demonstrating health-seeking behaviors. Most women in our sample lived in urban or peri-urban neighborhoods around Lilongwe and had higher educational attainment compared to the general population (i.e., 80% of the Malawians live in rural settings and 74% of Malawian women have primary education or less) [26], so perceptions may be different across populations. We also did not collect data prior to the educational talk and therefore could not formally assess changes in knowledge. Finally, the interviews took place up to five months after a participant's CBE screening, and could have been subject to recall bias..

In conclusion, our results indicate breast cancer education and CBE screening by laywomen were well received by Malawian women attending urban clinics. Asymptomatic women clearly acknowledged that breast cancer was an important health issue and were interested in being screened. They recommended that future programs continue to combine breast cancer education and screening in a manner that broadly targets community women throughout Malawi.

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Table 1

Characteristics of Malawian women interviewed about CBE screening experience (n=25)

	n	%
Age (mean)	43	
Rural residence	5	20%
Religion		
Christian	24	96%
Muslim	1	4%
Marital status		
Married	15	60%
Divorced or widowed	8	32%
Never married	2	8%
Education		
Less than secondary	6	24%
Some secondary	13	52%
Completed secondary or higher	6	24%
Socioeconomic position		
Electricity in home	16	64%
CBE result		
Normal CBE	17	68%
Abnormal CBE	7	28%
Refused to participate in screening	1	4%

Notes: CBE, clinical breast exam

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Table 2

Perceptions about screening programs and reasons given for choosing different options

	Breast cancer and screening	Cervical cancer and screening
Cancer site, location on body	“with breast cancer, I would not have any problems examining myself [...] and with cervical cancer, you need someone to do the examination.”	“Because it’s very hard for one to see the change in her cervix than on the breast, the cervical part is in a hidden place [...] as for the breast it’s very easy for one to see the change on the breast.”
Perceived severity of disease	“[Breast cancer is] dangerous because it spreads to a lot of our body parts unlike cervical cancer”	“It is the one which can spread rapidly.”
Disease awareness	“it is not common for breast cancer to be talked about, it is more difficult than cervical cancer because cervical cancer has been heard a lot in the past but about breast cancer, it seems like it has just started to be heard now”	“cervical cancer is common, most people know it and people have been informed about it for quite some time. They even talk about cervical cancer on television and hospitals, you can be examined because this cervical cancer is not difficult.”
Fear of treatment, surgical removal of body part	“in cervical cancer, they do cryotherapy if you have been found with signs of cancer and you will be well. While if don’t recognize breast cancer early and by the time you realize it, they will remove your breast and it may have already spread to other parts of the body.”	[cervical cancer is] “a very dangerous disease [...] when you have been found with it, they remove the uterus”
Screening procedure	“you told us that you [will] use hands to examine”	“They say doctors insert something like a metal bar in your vagina, so women become so afraid to be screened.”
Modesty, privacy	“You will not see my private parts. You will just examine my breasts”	“It is a private part and also that when you can have that chance [to be screened] it means you are very lucky because this doesn’t occur frequently.”