

East African Medical Journal Vol. 91 No. 11 November 2014

BARRIERS TO UPTAKE OF BREAST CANCER SCREENING IN KENYA

J. Wachira, PhD, MPH, A. F. Chite, Academic Model Providing Access to Healthcare (AMPATH) Partnership, Department of Medicine, School of Medicine, College of Health Sciences, Moi University, Eldoret, Kenya and Department of Medicine, School of Medicine, Indiana University, Indianapolis, United States, The Walther Project Team, V. Naanyu, Academic Model Providing Access to Healthcare (AMPATH) Partnership and Department of Behavioural Sciences, School of Medicine, College of Health Sciences, Moi University, Eldoret, The Walther Project Team, N. Busakhala, Academic Model Providing Access to Healthcare (AMPATH) Partnership and Department of Medicine, School of Medicine, College of Health Sciences, Moi University, Eldoret, The Walther Project Team, J. Kisuya, Academic Model Providing Access to Healthcare (AMPATH) Partnership, Eldoret, The Walther Project Team, A. Keter, A. Mwangi, Academic Model Providing Access to Healthcare (AMPATH) Partnership and Department of Behavioural Sciences, School of Medicine, College of Health Sciences, Moi University, Eldoret and T. Inui, Academic Model Providing Access to Healthcare (AMPATH) Partnership, Eldoret, Department of Medicine, School of Medicine, College of Health Sciences, Moi University, Eldoret, Kenya and Department of Medicine, School of Medicine, Indiana University, Indianapolis, United States, Regenstrief Institute, Inc. Indianapolis, United States and The Walther Project Team

Request for reprints to: J. Wachira, AMPATH Programmeme, P.O Box 4606, Eldoret Kenya, Email: wachirajuddy@gmail.com

BARRIERS TO UPTAKE OF BREAST CANCER SCREENING IN KENYA

J. WACHIRA, A. F. CHITE, V. NAANYU, N. BUSAKHALA, J. KISUYA, A. KETER, A. MWANGI and
T. INUI

ABSTRACT

Objectives: To conduct clinical breast cancer screening in three sites in Western Kenya and explore community barriers to screening uptake.

Design: Cross-sectional study.

Setting: Western Kenya specifically, Mosoriot, Turbo, and Kapsokwony.

Subjects: Community members (18 years and older) who did not attend the screening events.

Outcome Measure: The outcome measure was having heard about the breast cancer screening events. Both structured and open-ended questions were used for data collection. Item frequency, correlations, and content analyses were performed.

Results: A total of 733 community members were surveyed (63% women, median age 33 years, IQR=26-43). More than half (55%) of respondents had heard about the screening but did not attend. The majority of those who had heard about this particular screening had knowledge of screening availability in general (45% vs. 25%, $p < 0.001$). Only 8.0% of those who heard and 6.0% of those who had not heard of the screening event had previously undergone clinical breast exam ($p = 0.20$). Reasons for not attending the screening event were personal factors, including busy schedule (41.0%), perceived low personal risk (12.7%), lack of transport (4.2%), as well as health facility factors such as poor publicity (14.4%) and long queues (8.7%).

Conclusion: Barriers to breast cancer screening uptake were associated with inadequate publicity, perceived long waits at event and busy lives among community women.

INTRODUCTION

For decades, management of communicable diseases has been the main focus of health services in sub-Saharan Africa, with diseases like HIV creating the greatest burden of disease (1). In recent years, however, non-communicable diseases such as cancer are increasingly of great concern (1-4). According to health statistics in Kenya, cancer is the third highest cause of deaths in the country (4). It is estimated that

28,000 cases are reported each year and more than 20,000 annual deaths are cancer related (4). This has resulted in the establishment of a national policy to address the most common cancers in the region, with calls for a multi-sectoral and multi-disciplinary approach to cancer prevention and control (4).

Breast cancer is among the most common cancers and accounts for the highest cancer-related morbidity and mortality rates in the region (2-5). In Kenya, breast cancer (34 per 100,000) causes the highest mortality

and morbidity rates (4) in the region. Escalating incidences have been reported in women between the ages of 35 and 45 years (2). Even though breast cancer rates are reported to be lower in sub-Saharan countries compared to African subpopulations in developed countries, the need to establish effective breast cancer programmes in sub-Saharan countries cannot be overstated (2).

Unfortunately, breast cancer in Kenya has generally been characterised by the advanced stage of the disease, with 70–90% of women presenting in stage III or IV (2). Gynaecologic and reproductive factors, diet, body habitus, lifestyle, care-seeking behaviours, socio-economic status and family history have been cited as some of the risk factors in the region (2, 6). Prevention, early diagnosis, and timely treatment approaches are greatly needed to mitigate the adverse outcomes of the disease (5, 6). The region is, however, faced with a myriad of challenges to adequate breast cancer services, including limited funds, impoverished healthcare facilities, lack of mammography, low community awareness levels, and other existing health concerns, all of which limit breast cancer prevention and treatment services (2, 5–8).

Even with these limitations, breast cancer screening programmes that feature self- and clinical-breast examinations as well as mammograms (where available) have been advocated as critical steps towards creating awareness and promoting timely diagnosis and treatment (4, 6). There is, however, a need to promote the utilisation of these services within communities in different socio-cultural environments. We found no studies that have examined possible barriers to breast cancer screening uptake in Kenya, perhaps particularly in rural regions where the need may be greatest. We therefore conducted a community survey following breast cancer screening events in western Kenya. Our study objective was to explore community-level perceptions of barriers to participation in breast cancer screening.

MATERIALS AND METHODS

Study site: Academic Model Providing Access To Healthcare (AMPATH) was initiated in 2001 as a joint partnership between Moi University School of Medicine, the Indiana University School of Medicine, and the Moi Teaching and Referral Hospital (9). The initial goal of the programme was to establish an HIV care delivery system to serve the needs of both urban and rural patients. The programme operates in 25 Ministry of Health facilities with numerous satellite clinics in western Kenya. Over the years, AMPATH has expanded to embrace primary health care and chronic disease management including cancer. The AMPATH-Oncology Institute (AOI) was developed from the platform of the HIV-care programme to address the

care of cancer patients, for whom there were limited treatment options available. AMPATH-Oncology has evolved over time with the first services being paediatric oncology, which transitioned into care for AIDS-related malignancy, then to broad-based cancer treatment services, and most recently, a formally structured model for rationed care commensurate with the resource constraints and population burden of western Kenya. Within the AOI, the “Walther project” was initiated in 2011 when a grant was made by the Walther Cancer Foundation (“The IU Simon Cancer Center (IUSCC), AMPATH-Oncology Institute (AOI): An Exemplar of Care for the Developing World and a Population-based Research Environment for IUSCC”) in support of cancer research in Kenya. The Walther project has focused on cancer prevention activities and their evaluation, especially activities that respond to challenges in the AMPATH service area in western Kenya posed by breast cancer and cervical cancer.

Breast cancer screening programme: The Walther project personnel, working in collaboration with the AMPATH oncology team, conducted breast cancer screening events in October–November of 2012 at three AMPATH sites – Mosoriot (one-day event), Turbo (two-day event), and Kapsokwony (two-day event). In the absence of mammography availability, the screening services offered were clinician breast examination by well-trained health care providers (physician-oncologists). Individuals found to have a breast mass at these events were given a return date when biopsies were done to determine whether they had breast cancer. Care for those with cancer was provided at the western Kenyan national referral facility in Eldoret (Moi Teaching and Referral Hospital). All screening events were held at the ministry of health centres in the respective sites. One week before the events, posters, community meetings (*mabaraza*), and word of mouth through community health workers were used to publicise the screening events.

Study design: In each of the three screening event communities a cross-sectional survey was conducted between October–November 2012. The study targeted community members (18 years and older) who did not attend the breast cancer screening events. Systematic random sampling with replacement methods were used to identify the study sample, approaching random households along all access routes that extended from the health centre into its surrounding community. Ethical approval for the study was obtained from the Moi University Institutional Research and Ethics Committee (IREC) as well as the Indiana University Institutional Review Board (IRB).

Study procedure: The survey was administered in one of two preferred languages (English or Swahili) by trained research personnel at the household level. Written consent was obtained from all participants prior to their participation in the study. Recruitment questions were first administered to determine eligibility for the main survey. The main survey included open-ended and structured forced-choice items. The structured items included:

- 1) socio-demographic characteristics including age, sex (male vs. female); relationship status (married vs. single/separated/divorced/widowed);
- 2) socio-economic characteristics including education level (secondary and lower vs. tertiary); occupation (non-employed vs. employed and casual laborer); means of transport to health care (walking vs. public or private vehicles) and time required to travel to the health facility (in minutes);
- 3) previous breast exams which included having felt a breast lump (yes vs. no) and having ever undergone any breast cancer screening (yes vs. no);
- 4) having been trained how to feel for a breast lump (yes vs. no);
- 5) knowledge of availability of breast cancer screening programmes (yes vs. no) and having heard about the screening events (yes vs. no); and
- 6) perceived barriers to clinical breast exam if breast changes were noted (yes vs. no/don't know). An open-ended question focused on reason(s) for not attending the current screening event and was only asked of those who had heard about the screening event but had not attended. Finally, in another open-ended question with structured prompts, respondents were asked for their preferences for learning about future screening events.

Data analyses: Responses to open-ended questions were recorded verbatim and translated into English. These data were then coded, and themes related to barriers to uptake of breast screening were identified, pooled and integrated into larger categories. To assure reliability of coding, independent coding and identification of themes were conducted by three investigators with negotiation of any identified differences. Quantitative data were analyzed using SAS version 9.3 and STATA version 11.0. Descriptive analyses including mean, median, interquartile range (IQR) and selected correlations were performed. Bivariate analysis was performed to explore potential differences between those who had heard about the screening event and those who did not. Pearson's Chi Square test was used for categorical variables and two-sample Wilcoxon rank sum test for

continuous variables. Explanatory variables included socio-demographic characteristics, socio-economic characteristics, having previously undergone breast exams, having been trained to feel for a breast lump, knowledge of breast cancer screening, and perceived barriers to breast examination.

RESULTS

A total of 733 community members who did not attend the advertised breast cancer screening events were surveyed within one day of the screening events. The median age of respondents was 33 years (IQR=26-43) and women represented 63% of the sample. There were no significant socio-demographic or socio-economic differences between those who had heard about the screening events and those who had not. The majority of respondents (73%) were married, and a half had completed at least a secondary level of education. A higher number (68%) were self-employed with farming being the main source of income. On average respondents took 30 minutes to travel to the health facility with walking (53%) being the most common mode of transport.

Even though about a third (36%) of the respondents stated that they had previously felt a lump in their breast, only 14% reported that they had been trained to check for breast lumps and only 8% reported having undergone breast cancer screening. Slightly more than half (55%) of respondents had heard about the breast cancer screening event but did not attend (see Table 1). A higher percent of those who had heard about this particular screening event reported knowing about the availability of breast cancer screening services in general (45% vs. 25%, $p=0.001$). However only 8.0% of those who heard and 6.0% of those who had not heard of the screening event had previously undergone breast cancer screening ($p=0.20$). There were no significant differences in all other relevant variables between those who had heard vs. those who had not heard about the screening events. Similarly, there were no significant differences in perceived barriers to clinical breast exams, where the majority of respondents perceived no potential barriers to seeking medical services if they noted changes in their breast (Table 2). Even though a relatively infrequent response, the perceived high cost of seeking medical care was the most common (22%) reported barrier. Only 3% reported potential embarrassment at breast examinations, 4% fear of outcome of screening and 5% negative influence of significant others (including husband, wife, sibling, partner, relative or friend) who might dissuade them from participating in screening.

Table 1
Participant characteristics by knowledge of breast cancer screening event

Variable	Sample size	Total (n=733), n(%) or Median (IQR)	Heard about screening (n=403), n (%) or Median (IQR)	Did not hear about screening, (n=330) n (%) or Median (IQR)	P value
Age (years)	730	33(26-43)	32(26-42)	34(25-46)	0.685
Sex (Male vs. Female)	733	268(37)	142(35)	126(38)	0.410
Marital status (Married vs. single / separated / divorced / widowed)	733	534(73)	304(75)	230(70)	0.082
Education (secondary and lower vs. tertiary)	733	365(50)	210(52)	155(47)	0.166
Occupation	733				
• Employed		153(21)	83(21)	70(21)	
• Self-employed		501(68)	284(70)	217(66)	0.147
• Unemployed		78(11)	35(9)	43(13)	
Means of transport (walking vs. public or personal vehicle)	730	389(53)	224(56)	165(50)	0.145
Time required to reach health center (minutes)	727	30(15-30)	30(20-30)	30(15-30)	0.655
Have you felt your breast for lumps? (Yes vs. No)	729	236(32)	124(31)	112(34)	0.382
Have you been trained on how to feel your breast for a lump? (Yes vs. No)	729	99(14)	56(14)	43(13)	0.715
Are you aware of any breast screening available (Yes vs. No)	732	263(36)	180(45)	83(25)	<.0001
Have you ever undergone any breast cancer screening? (Yes vs. No)	728	55(8)	35(9)	20(6)	0.199

Table 2
Perceived barriers to clinical breast cancer screening by knowledge of breast cancer screening event

Variable	Sample size	Total (n=733), n(%) or Median (IQR)	Heard about screening (n=403), n (%) or Median (IQR)	Did not hear about screening, (n=330) n (%) or Median (IQR)	Pvalue
Too embarrassed to go and see the doctor (Yes vs. No/Don't know)	733	20(3)	11(3)	9(3)	0.999
Too scared to go and see the doctor (Yes vs. No/Don't know)	733	31(4)	19(5)	12(4)	0.470
Too busy to make time to go to the doctor (Yes vs. No/Don't know)	730	52(7)	33(8)	19(6)	0.207
Worried about what doctor may find (Yes vs. No/Don't know)	733	66(9)	40(10)	26(8)	0.335

Not feeling confident talking about my symptoms with the doctor (Yes vs. No/Don't know)	733	39(5)	20(5)	19(6)	0.633
I find the doctor difficult to talk to (Yes vs. No/Don't know)	733	31(4)	18(4)	13(4)	0.724
Expensive to see a doctor(Yes vs.No/Don't know)	733	162(22)	91(23)	71(22)	0.729
Would significant people in your life not approve of you seeing a doctor or nurse (Yes vs. No/Don't know)	733	39(5)	21(5)	18(5)	0.884
My doctor does not understand my language(Yes vs. No/Don't know)	733	55(8)	31(8)	24(7)	0.830
My doctor does not understand my culture (Yes vs. No/Don't know)	733	57(8)	33(8)	24(7)	0.645

Among those who had heard of the screening event, the reasons for not attending included personal and health facility factors. Personal factors were recorded as having a busy schedule 177(41.0%), perceived low personal risk 51 (12.7%), lack of transport 17 (4.2%) and perceived poor quality of health services 13(3.2%). Survey respondents who had not sought screening reported that the screening events were held at times when they were either busy at work or performing their daily house chores. Those individuals who felt that they were at a lower risk of acquiring breast cancer were not motivated to get screened, especially given the cost implication (time and money) associated with attending the events. Lack of transport was associated with lack of finances to pay for public transportation to the breast cancer screening venue.

Given that all the screening events were held at the ministry of health facilities, perception of poor quality of health service was based on previous experiences with the respective health facilities and not necessarily the quality of the special screening being offered. Health facility factors such as inadequate publicity 58 (14.4%) and long queues 35 (8.7%) were also cited. Participants complained that the breast cancer screening publicity approaches used did not provide adequate information about the date, duration, and venue. It was also stated that the announcement provided short notice for community members who had busy schedules. Those who cited long queues as a barrier reported that they tried to attend the event but were not screened because of the long queues. Other barriers were reported as forgetfulness, laziness, fear of screening procedures and outcomes, and bad weather. There were no significant gender differences in the responses provided. A majority (94.7%) of respondents preferred that future communication about breast cancer screening be done through the local or national radio stations.

DISCUSSION

Breast cancer is increasingly becoming a significant cause of morbidity and mortality in sub-Saharan Africa (3, 4, 6, 10) in general and in western Kenya in particular. Promoting breast cancer awareness, screening and treatment programmes is critical to addressing breast cancer outcomes (5, 6, 10). Our findings show that in our region of Kenya (2, 3), breast cancer screening knowledge and uptake of special screening services remain low. Even knowing that breast screening programmes in general were available did not translate into uptake of special screening services when offered, with slightly more than half of our respondents having heard of the screening but not attending. Unlike previous studies in developed countries that identified emotional barriers such as fear, anxiety and worry about the outcome of screening (11) as major barriers to screening uptake, our findings suggested that concerns about structural factors such as poor publicity, long waits at health centers, and the inconvenience of single-day events that interfered with busy personal schedules were more important. In addition perceived low personal risk and the transport costs for seeking clinical screening services were cited as barriers. Breast cancer programmes in Kenya will need to overcome some of these barriers if greater penetrance of screening is to be achieved. This might be realized by tailoring the screening programmes to various socio-cultural environments and distinguishing special screening events from usual services.

Our study also revealed that even though a number of respondents had felt a lump in their own breast, very few had been trained to perform self-examination or actually undergone a clinical breast exam. Although studies in resource-intensive countries have reported that self-breast examination

may not be effective for early diagnosis of breast cancer, there is a general appreciation that breast exams increases awareness of breast changes that may prompt women to seek medical advice(12). This is critical for resource limited settings like Kenya where the availability of mammography may not be readily available (6, 10). A combination of self- and annual-clinical breast exams may be the best option for our resource-scarce region.

Even with annual special screening events in targeted areas preceded by posters, community gatherings, and word-of-mouth announcements, less than half of community residents were aware of the breast screening events. This lack of uptake may reflect limited investment in breast cancer awareness and prevention programmes in the Kenyan national health care system, given the limited resource and the prioritization of other impending health concerns in the region (2, 5-8). Only recently did Kenya establish a national policy to address breast cancer(among other cancers)(4) as majority of the focus has been on managing infectious diseases like HIV. There is need to build upon existing health care delivery systems and integrate cancer prevention and treatment into the current care system.

Our study findings highlight the importance of effective community awareness/publicity/mobilisation approaches for promoting breast cancer screening uptake. In this region radio announcement was the most preferred approach, which had not been previously used to inform communities about the screening events. Future breast cancer screening campaigns in the region will need to consider these findings as well as addressing the potential structural barriers cited. Specific consideration of the social cultural environment that ultimately defines the comprehension and coverage of the messages, as well as the accessibility of screening services is vital. It is important to appreciate that in resource-limited environments community members may place more emphasis on securing their basic needs rather than seeking preventive care services. Even though a majority reported that they would not be too busy to go seek medical services if they noted changes in their breast, having a busy schedule were cited as a barrier to screening uptake. In order to maximise screening uptake the messaging, publicity, venue of the screening and duration of screening (including appropriate times for the screening events) may all need to be tailored for communities. Community participatory approaches should be emphasised with members fully engaged in every stage of the breast cancer screening campaigns design and implementation.

LIMITATION

Even though our study provides valuable insight on the barriers to breast screening uptake in Kenya, it is not without limitation. In this study we are only able to describe the characteristics of those who did not participate in special breast cancer screening days. Knowing the difference between those who did and did not participate in screening may be important for inferences about how to facilitate more participation. Though our respondents were drawn from three different communities, our study findings cannot be generalised to the entire Kenya population.

In spite of these limitations, we believe that our study provides important preliminary information that may be useful in attempts to enhance uptake of breast cancer screening services in western Kenya. We highlight some of the challenges breast cancer screening campaigns may face as they launch special events to promote high coverage of breast cancer awareness and uptake of screening services. Effective public awareness of breast cancer, appropriate publicity of special screening events, and perceived quality of breast cancer screening services will need to be considered in future events. Early announcements through the local radio stations, and engaging communities in the planning and implementation of the screening events is critical for this region. In addition, efforts to equip health facilities with the capacity to conduct routine breast cancer screening in the course of primary care may be needed in addition to mobilization for special screening events.

ACKNOWLEDGEMENTS

To the Walther Cancer Foundation and the AMPATH-Oncology Institute (AOI) for their support of this study as well as cancer research in Kenya.

We also acknowledge donors of the AMPATH-Oncology Institute which include: Levinson Family Foundation; Pfizer Foundation; Pfizer Oncology Business Unit; Eli Lilly & Co.; Roche Pharmaceuticals; Walther Foundation; USAID; Haemophilia and Thrombosis Centre of Indianapolis.

REFERENCES

1. The World Bank: The global burden of disease: Generating evidence guiding policy. In. Washington, USA: The World Bank; 2013.
2. Fregene A, Newman LA: Breast cancer in sub-Saharan Africa: How does it relate to breast cancer in African-American women? *Cancer* 2005, **103**:1540-1550.
3. Sankaranarayanan R, Ferlay J: Burden of Breast and Gynecological Cancers in Low-Resource Countries.

- In: Breast and Gynecological Cancers. Edited by Shetty MK: Springer New York; 2013: 1-17.
4. Ministry of Health: National cancer control strategy 2011-2016. In. Nairobi, Kenya: Ministry of Public Health and Sanitation and the Ministry of Medical Services; 2011.
 5. Panieri E: Breast cancer screening in developing countries. *Best Practice & Research Clinical Obstetrics & Gynaecology* 2012, **26**:283-290.
 6. Kelly K, Shetty M, Fregnani J: Breast Cancer Screening and Cervical Cancer Prevention in Developing Countries: Strategies for the Future. In Breast and Gynecological Cancers. Edited by Shetty MK: Springer New York; 2013: 301-329.
 7. Zelle SG, Baltussen MR: Economic analyses of breast cancer control in low- and middle-income countries: A systematic review. *Syst Rev* 2013, **2**:20.
 8. Anderson BO, Yip C-H, Ramsey SD, Bengoa R, Braun S, Fitch M, Groot M, Sancho-Garnier H, Tsu VD, for the Global Summit Health Care S *et al*: Breast Cancer in Limited-Resource Countries: Health Care Systems and Public Policy. *The Breast Journal* 2006, **12**:S54-S69.
 9. Einterz RM, Kimaiyo, S., Mengech, H. N., Khwa-Otsyula, B. O., Esamai, F., Quigley, F., & Mamlin, J. J: Responding to the HIV pandemic: the power of an academic medical partnership. *Academic Medicine* 2007, **82**:812-818.
 10. Shyyan R, Masood S, Badwe RA, Errico KM, Liberman L, Ozmen V, Stalsberg H, Vargas H, Vass L, for the Global Summit D *et al*: Breast Cancer in Limited-Resource Countries: Diagnosis and Pathology. *The Breast Journal* 2006, **12**:S27-S37.
 11. Consedine NS, Magai C, Krivoshekova YS, Ryzewicz L, Neugut AI: Fear, Anxiety, Worry, and Breast Cancer Screening Behavior: A Critical Review. *Cancer Epidemiology Biomarkers & Prevention* 2004, **13**:501-510.
 12. J P Kösters, Götzsche PC: Regular self-examination or clinical examination for early detection of breast cancer. *Cochrane Database of Systematic Reviews* 2003(2).