ORIGINAL ARTICLE

Observational Study

Lay perceptions of breast cancer in Western Kenya

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Abstract

AIM: To explore lay perceptions of causes, severity, presenting symptoms and treatment of breast cancer.

METHODS: In October-November 2012, we recruited men and women (18 years and older) from households and health facilities in three different parts of Western Kenya, chosen for variations in their documented burdens of breast cancer. A standardized and validated tool,

the breast cancer awareness measure (BCAM), was administered in face-to-face interviews. Survey domains covered included socio-demographics, opinions about causes, symptoms, severity, and treatment of breast cancer. Descriptive analyses were done on quantitative data while open-ended answers were coded, and emerging themes were integrated into larger categories in a qualitative analysis. The open-ended questions had been added to the standard BCAM for the purposes of learning as much as the investigators could about underlying lay beliefs and perceptions.

RESULTS: Most respondents were female, middle-aged (mean age 36.9 years), married, and poorly educated. Misconceptions and lack of knowledge about causes of breast cancer were reported. The following (in order of higher to lower prevalence) were cited as potential causes of the condition: Genetic factors or heredity (n = 193, 12.3%); types of food consumed (n = 187, 11.9%); witchcraft and curses (n = 108, 6.9%); some family planning methods (n = 56, 3.6%); and use of alcohol and tobacco (n = 46, 2.9%). When asked what they thought of breast cancer's severity, the most popular response was "it is a killer disease" (n = 266, 19.7%) a lethal condition about which little or nothing can be done. While opinions about presenting symptoms and signs of breast cancer were able to be elicited, such as an increase in breast size and painful breasts, early-stage symptoms and signs were not widely recognized. Some respondents (14%) were ignorant of available treatment altogether while others felt breast cancer treatment is both dangerous and expensive. A minority reported alternative medicine as providing relief to patients.

CONCLUSION: The impoverished knowledge in these surveys suggests that lay education as well as better screening and treatment should be part of breast cancer control in Kenya.

Key words: Breast cancer; Health education; Cancer control; Lay health beliefs

Core tip: A survey of women's knowledge and beliefs about breast cancer causes, presentation, and treatment in Western Kenya uncovered significant ignorance and misperceptions. Effective approaches will be needed to remediate this situation if Kenyan national aspirations for breast cancer control are to succeed.

INTRODUCTION

Breast cancer has become a significant cause of morbidity and mortality globally. Developing countries are especially affected and are increasingly reporting more cases worldwide. In many developing countries, breast cancer care is not a priority for there are many other health priorities and limited health budgets. Consequently, these nations offer minimal attention to cancer, even while it is becoming a leading cause of death[1]. They also do not have organized data registries, thus they lack reliable data on breast cancer incidence, mortality, survival, and stage of presentation[2,3].

Factors associated with increased breast cancer incidence include increased life expectancy, reduction in competing risk of mortality from infections, change in reproductive patterns, and changes in lifestyles[4-6]. To compound the difficulties imposed by its rising incidence, breast cancer patients in developing countries enroll late for treatment. This delay has been associated with several factors. First, low levels of community and even health providers' awareness of breast cancer results in widespread ignorance about the problem. Second, many patients encounter barriers as they attempt to access appropriate treatment. Third, some find it extremely frustrating to access health care systems in some regions. Alternative health belief models and associated traditional, complementary health care systems persist. Lastly, breast cancer early detection programs are scarce[7-11].

In East Africa, the breast cancer incidence rate estimate is 19.3 per 100000 women[12]. Breast cancer is the most prevalent cancer among Kenyan women, and constitutes a major public health problem[13,14]. Although definite data are lacking for Kenya, estimates indicate that breast cancer accounts for about 23% of all cancers in the country[15]. Unfortunately, Kenya has not developed a comprehensive cancer surveillance system and there is no national population-based cancer registry[15]. Without representative data, a data-based and discerning national profile of the health burden of breast cancer is unattainable. Lack of routinely collected data hampers public policy response to the problem.

According to the Kenya Medical Research Institute (KEMRI), about 80% of reported cases of cancer are diagnosed at advanced stages, when very little can be achieved in terms of curative treatment[15]. Perhaps in response, the Kenyan government has launched a National Cancer Control Strategy that prioritizes cancer prevention and control. This strategic plan covers the period 2011 to 2016 and proposes a strategic foundation for cancer control and prevention, outlines a vision and mission, and recommends specific interventions and objectives as suitable for Kenya. Ultimately, the strategic plan aims to reduce the number of people who develop and die of cancer while ensuring a better quality of life for those still affected by the disease[15].

Since low public awareness and/or negative beliefs

about breast cancer have been noted as a contributor to potentially preventable deaths in breast cancer programs, we undertook a project to explore breast cancer awareness, knowledge and practices among men and women of Western Kenya in order to provide information that will guide subsequent prevention and treatment efforts. This particular paper reports descriptive data from the project, focusing especially on lay beliefs that emerged about causes, severity, presenting symptoms and treatment of breast cancer.

MATERIALS AND METHODS

A cross-sectional study was conducted by a research team from the Academic Model Providing Access to Healthcare (AMPATH) program in Eldoret. AMPATH is a collaboration of Moi University School of Medicine, Moi Teaching and Referral Hospital (MTRH), the Kenyan Ministry of Health, and a consortium of North American Universities[16]. This project was embedded in the AMPATH Oncology Institute (AOI) and was supported by the Walther Cancer Foundation of Indianapolis, indiana United States data were collected in three communities served by AMPATH, including Turbo, Mosoriot and Kapsokwony between October-November 2012. The study sites were chosen on the basis of unpublished data from the Eldoret Cancer Registry to represent counties with high, and low burdens of breast cancer. Within the Cancer Registry, the largest number of breast cancer cases come from Uasin Gishu County (45%) where Turbo is located. Mosoriot community is in Nandi County and contributes 5% of breast cancer cases to the registry, while Mount Elgon provides the lowest number of cases to the registry (0.2%) and includes the community of Kapsokwony. The ethnic composition of these three counties taken together is reasonably representative of the ethnic communities of the whole AMPATH service area population of Western Kenya.

The study surveyed women (18 years and older) who voluntarily presented to their respective health facilities for special breast screening days as well as general community members living in the near vicinity of the health center. Ethical approval for the survey was obtained from the MTRH Institutional Research and Ethics Committee as well as the Indiana University Institutional Review Board.

The study survey instrument was in large part a standardized and validated survey questionnaire, one developed for assessment of breast cancer awareness in United Kingdom - the Breast Cancer Awareness Measure (BCAM)[17]. BCAM items were written to characterize beliefs in seven domains: knowledge of symptoms of breast cancer; women's confidence, skills and behavior in detecting a breast change; anticipated delay in contacting the doctor on discovering a symptom; barriers to seeking medical help; knowledge of age-related and lifetime risk of breast cancer; knowledge of any breast screening programs. For this study we modified the BCAM to include items of particular relevance in

this Kenyan setting and added open-format, free-text inquiries about breast cancer. These questions were two in number: (1) "What are some beliefs, opinions, or traditions you have heard from others about breast cancer?" (in Kiswahili, Ni baadhi ya maoni ama tamaduni zipi ambazo umewahi kusikia kutoka kwa watu wengine kuhusu saratani ya matiti?); and (2) "In your opinion, what are some of the early warning signs of breast cancer, the ways in which one may know first that s/he has this condition?" (Kwanza habisa, kwa maoni yako ni, dalili gani za mapema zinazotahadharisha kuhusiana na saratani ya matiti? Yani njia ambzao mtu anaweza kutambua mapema kuwa anaugua huu ongonjwa?). The resultant tool was translated to Kiswahili, the national language, and was tested for understandability and completeness in three 1-2 h focus group discussions (FGDs) prior to fielding the survey. The FGDs included men and women who were > 18 years of age, drawn from those attending outpatient clinics for non-cancer related conditions. Individuals with current or previous diagnosis of cancer were excluded from the validation activity.

In the community and health center surveys, trained research assistants sought written consent and administered the validated semi-structured tool that facilitated collection of data on several topics. The socio-demographic tool was structured, while opinions about causes, symptoms, severity, and treatment of breast cancer were captured as free-text responses to the open-ended queries added to the BCAM. Responses to these questions were recorded verbatim and translated into English as necessary. These data were then coded, and emerging themes 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. Descriptive analyses were done on quantitative data using Statistical Analysis System version 9.3 and STATA version 11.0. Each coded statement was viewed as a variable, and each respondent could have multiple responses to a single question. Tables 1 and 2 report frequency/percentage for each coded statement type, summarizing statements from a total of 1335 study participants in the three communities. In reporting these data we have pooled responses from all surveyed participants - those interviewed in the health centers and those interviewed in the communities served by the health centers - because in preliminary analyses the distribution of opinions from these two samples were not different.

RESULTS

Participant characteristics
This study enrolled a total of 1335 participants, 481 participants from Kapsokwony, 277 from Mosoriot and 577 from Turbo. Five-hundred and ninety-four of the participants were surveyed at the health centers and the remainder in community households in the near vicinity.

Table 1 Lay opinions about causes of breast cancer in Western Kenya

| Perceived cause | No. of coded statements (%) | | | |
	Kapsokwony 597 (38%)	Mosoriot 297 (19%)	Turbo 672 (43%)	Total Opinions 1566 (100%)
Hereditary	91 (15.2)	33 (11.1)	69 (10.3)	193 (12.3)
Food consumed	60 (10.1)	38 (12.8)	89 (13.2)	187 (11.9)
Witchcraft and curses	63 (10.6)	7 (2.4)	38 (5.7)	108 (6.9)
Family planning methods	23 (3.9)	8 (2.7)	25 (3.7)	56 (3.6)
Alcohol and tobacco consumption	18 (3.0)	2 (0.7)	26 (3.9)	46 (2.9)
Breastfeeding	12 (2.0)	8 (2.7)	8 (1.2)	28 (1.8)
Not breastfeeding	9 (1.5)	6 (2.0)	9 (13)	24 (1.5)
Exposure to toxic substances	11 (1.8)	4 (1.3)	7 (1.0)	22 (1.4)
HIV and other sexual diseases	6 (1.0)	0	3 (0.4)	9 (0.6)
Environmental changes	2 (0.3)	2 (0.7)	4 (0.6)	8 (0.5)
Radiation and vibrations	7 (1.2)	0	1 (0.1)	8 (0.5)
Type of clothing	2 (0.3)	0	4 (0.6)	6 (0.4)
Low sexual encounters	1 (0.2)	0	1 (0.1)	2 (0.1)
Early sexual encounter	2 (0.3)	0	0	2 (0.1)
High number of sexual encounters	1 (0.2)	0	1 (0.1)	2 (0.1)
Others[1]	25 (4.2)	5 (1.7)	13 (1.9)	43 (2.7)
No opinions expressed[2]	264 (44.2)	184 (61.9)	374 (55.7)	822 (52.5)

[1]Others include: Becoming rich/wealthy, depression, dirt in the body, bacterial infection, injuries, traditional medicine not properly administered, not "having children", man sucking on breasts during pregnancy, male circumcision, fate, insect bites, lack of physical activity, and having big breasts; [2]N in this row = number of respondents expressing no opinions.

Table 2 Lay perceptions of severity and symptoms/signs of breast cancer in Western Kenya

| Perception | No. coded statements (%) | | | |
	Kapsokwony 489 (36%)	Mosoriot 280 (21%)	Turbo 580 (43%)	Total Perceptions 1349 (100%)
Severity				
Killer disease	105 (21.5)	45 (16.1)	116 (20.0)	266 (19.7)
Breasts are removed	10 (2.0)	3 (1.1)	12 (2.1)	25 (1.9)
Curable if detected early	10 (2.0)	6 (2.1)	2 (0.3)	18 (1.3)
A disease like any other	5 (1.0)	6 (2.1)	3 (0.5)	14 (1.0)
It does not exist	3 (0.6)	1 (0.4)	0	4 (0.3)
Spreads to rest of the body	2 (0.4)	1 (0.4)	0	3 (0.2)
Cancer eats away the breast	0	1 (0.4)	0	1 (0.1)
Don't know	354 (72.4)	217 (77.5)	447 (77.1)	1018 (75.5)
Symptoms/signs				
	1166 (40%)	552 (19%)	1192 (41%)	2910 (100%)
Changes in breast size	207 (17.8)	109 (19.7)	266 (22.3)	582 (20.0)
Pain, tingle or tenderness of the breast	195 (16.7)	88 (15.9)	243 (20.4)	526 (18.1)
Lump in breast	165 (14.2)	72 (13.0)	129 (10.9)	366 (12.6)
Discharge from the breast	163 (13.9)	58 (10.5)	131 (11.0)	352 (12.1)
Wound on the breast	92 (7.9)	39 (7.1)	90 (7.6)	221 (7.6)
Itching	80 (6.9)	17 (3.1)	68 (5.7)	165 (5.7)
Change in breast skin color	44 (3.8)	17 (3.1)	27 (2.3)	88 (3.0)
Rash on breast and skin peeling	30 (2.6)	8 (1.4)	20 (1.7)	58 (2.0)
Change in nipples	21 (1.8)	10 (1.8)	17 (1.4)	48 (1.6)
Swelling in any other parts of the body	11 (0.9)	8 (1.4)	7 (0.6)	26 (0.9)
General symptoms[1]	28 (2.4)	33 (6.0)	26 (2.2)	87 (3.0)
Don't know	130 (11.1)	93 (16.8)	168 (14.1)	391 (13.4)

[1]General symptoms include fatigue, chest pain, loss of weight, change in eye color, liver trouble, no appetite, sweating, cough, chills, and fever.

In both surveys, the number of respondents was limited only by the capacity of trained interviewers to administer the BCAM, since almost all potential participants approached were willing to participate, but the interviewers had to limit their workdays to catch transportation back to Eldoret. In the health center sample, attendees were given the option to be interviewed after completing an informed consent document. If attendees wished to skip the interview and proceed directly to clinical breast examination, they were given this choice. A total of 1511 volunteers (1238 women and 273 men) presented themselves to the health centers for CBE screening and about 48% (594) of this number were interviewed. In the community surveys, research assistants were dispatched in groups of 2 or 3 and walked or were driven to specific locations within the administrative units of the

Table 3 Demographics of participants in Breast Cancer Awareness Measure survey in Western Kenya

Participant attribute		Kapsokwony (*n* = 481)	Mosoriot (*n* = 277)	Turbo (*n* = 577)	Total (*n* = 1335)
		n (%)	*n* (%)	*n* (%)	*n* (%)
Age (yr)	⩽ 30	187 (38.9)	114 (41.2)	223 (38.9)	524 (39.3)
	31-60	265 (55.1)	142 (51.3)	320 (55.5)	727 (54.5)
	61-90	28 (5.8)	17 (6.1)	31 (5.4)	76 (5.7)
	91+	0	2 (0.7)	1 (0.2)	3 (0.2)
	Missing data	1 (0.2)	2 (0.7)	2 (0.4)	5 (0.4)
Sex	Female	414 (86.1)	198 (71.5)	449 (77.8)	1061 (79.5)
	Male	67 (13.9)	79 (28.5)	126 (21.8)	272 (20.4)
	Missing data	0	0	2 (0.4)	2 (0.2)
Marital status	Married	383 (79.6)	202 (72.9)	423 (73.3)	1008 (75.5)
	Single	60 (12.5)	59 (21.3)	121 (20.9)	240 (18.0)
	Divorced	3 (0.6)	0	3 (0.5)	6 (0.5)
	Separated	10 (2.1)	8 (2.9)	14 (2.4)	32 (2.4)
	Widowed	25 (5.2)	8 (2.9)	14 (2.4)	47 (3.5)
	Missing data	0	0	2 (0.4)	2 (0.2)
Education	None	31 (6.4)	14 (5.1)	37 (6.4)	82 (6.1)
	Primary	193 (40.1)	130 (46.9)	253 (43.9)	576 (43.2)
	Secondary	160 (33.3)	94 (33.9)	202 (35.0)	456 (34.2)
	Certificate/diploma	87 (18.1)	35 (12.6)	67 (11.6)	189 (14.2)
	University	10 (2.1)	4 (1.4)	16 (2.8)	30 (2.3)
	Missing data	0	0	2 (0.4)	2 (0.2)
Occupation	Business	84 (17.5)	33 (11.9)	136 (23.6)	253 (19.0)
	Casual laborer	9 (1.9)	15 (5.4)	19 (3.3)	43 (3.2)
	Employed	100 (20.8)	58 (20.9)	93 (16.1)	251 (18.8)
	Farming	157 (32.6)	63 (22.7)	121 (21.0)	341 (25.5)
	Self employed	22 (4.6)	17 (6.1)	30 (5.2)	69 (5.2)
	Unemployed	105 (21.8)	91 (32.9)	176 (30.5)	372 (27.9)
	Missing data	4 (0.8)	0	2 (0.4)	6 (0.5)
Transportation	Boda boda	138 (28.7)	53 (19.1)	79 (13.7)	270 (20.2)
	Car	2 (0.4)	9 (3.3)	8 (1.4)	19 (1.4)
	Matatu	25 (5.2)	88 (3.2)	227 (39.3)	340 (25.5)
	Walking	314 (65.3)	122 (44.0)	259 (44.9)	695 (52.1)
	Other	1 (0.2)	4 (1.4)	0	5 (0.4)
	Missing data	1 (0.2)	1 (0.4)	4 (0.7)	6 (0.5)

district served by the health center. From these drop-off points the interviewers chose the first household at random, after which they would proceed to every third household until they reached the target sample size for the day (or the transport back was ready to depart). The community resident survey used the same BCAM and was conducted the day following the screening special event. A total of 741 respondents participated in community surveys.

As shown in Table 3, most respondents were female and married. The mean age was 36.9 (SD = 13.7) years and very few (19.3%, 10% and 21% in Kapsokwony, Mosoriot and Turbo respectively had post-secondary education. A small proportion reported no formal education at all, with Turbo showing the highest proportion of the uneducated (*n* = 37, 3%). Three-hundred and seventy-two respondents (28%) reported unemployment. Not less than 8%, 7% and 13% were unemployed in Kapsokwony, Mosoriot and Turbo respectively. The most common occupations were farming (*n* = 341, 26%), business (*n* = 253, 19%), and employed positions (*n* = 251, 19%). The most common means of transport to health care included walking (52%), use of public small-van transportation (matatu) (25%) and motorcycle taxis (bodaboda) (20%).

Causes of breast cancer: In Table 1, we present data on perceptions of the causes of breast cancer. In general, perceptions are similar across sites. A majority of respondents could offer no opinions about probable causes of this condition. Altogether, 822 or more than half of those surveyed (52.5%) had no specific knowledge of the factors that may cause breast cancer. Among those with opinions about causality, the following (in order of higher to lower prevalence) were cited as potential causes of the condition: genetic factors or heredity (*n* = 193, 12.3%); types of food consumed (*n* = 187, 11.9%); witchcraft and curses (*n* = 108, 6.9%); some family planning methods (*n* = 56, 3.6%); and use of alcohol and tobacco (*n* = 46, 2.9%). Compared to other sites, Mosoriot respondents less often cited the possible role of substance abuse and family planning methods: only two participants attributed breast cancer to substance abuse while another eight implicated family planning.

Other causes reported by a few respondents included fertility, pregnancy and breastfeeding practices; environmental factors (toxins, radiation, vibrations); diverse sexual behaviors (few/high encounters, early debut); wearing of tight-fitting clothing, poor mental health; dirty bodies; presence of other diseases and

unfitting use of medicines; lack of exercise; male circumcision; and having large breasts.

Severity of breast cancer: As shown in Table 2, when asked what they thought of breast cancer's severity, the most popular response was "it is a killer disease" (*n* = 266, 19.7%) a lethal condition about which little or nothing can be done. A smaller number of respondents believed that it can be cured if found early (18, 1.3%) and it is a disease like any other (*n* = 14, 1%). Surprisingly, a few said breast cancer doesn't exist (*n* = 4, 0.3%). No less than 25 participants in Kapsokwony (*n* = 10), Mosoriot (*n* = 3) and Turbo (*n* = 12) discussed removal of breasts as they considered the severity of breast cancer.

Symptoms and signs of breast cancer: The most common symptoms/signs of breast cancer cited across all three communities were typical of late-stage disease (Table 2): changes in breast size (*n* = 582, 20%); pain, tingling or tenderness of the breast (*n* = 526, 18.1%); growth of a lump in the breast (*n* = 366, 12.6%); presence of a discharge of pus or blood from the breast (*n* = 352, 12.1%); development of a wound on the breast - including occurrence of a bad smell and maggots (*n* = 221, 7.6%); and itching (*n* = 165, 5.7%). Other less-often cited symptoms included: change in breast skin color (*n* = 88, 3%); development of a rash on the breast and peeling of the skin (*n* = 48, 1.6%); and changes in nipples including size and direction (*n* = 48, 1.6%). About 22.8% (*n* = 304) of the total study sample did not cite any presenting breast cancer symptom or signs. This represents 20%, 26% and 24% of participants from Kapsokwony, Mosoriot and Turbo sites respectively.

Management of breast cancer: In other BCAM structured question responses, lay opinions on breast cancer management showed 14% (*n* = 185) of all respondents (1335) were completely ignorant of available treatment (17%, 14% and 11% of Kapsokwony, Mosoriot and Turbo sites respectively). Some (*n* = 95, 7.1%) believed complementary alternative medicine provides relief to breast cancer patients. A few (*n* = 18, 1.4%) thought it is potentially curable, however, 7 (0.5%) said breast cancer treatment is expensive. Other rare opinions suggested mastectomy causes death (*n* = 7, 0.5%), biopsy spreads cancer in the body (*n* = 5, 0.4%), and the disease attracts social stigma (*n* = 7, 0.5%).

DISCUSSION

This study illustrates the productivity of using open-ended, free-text inquiry as an element in surveys intended to explore the prevalence of perceptions and beliefs about a condition like breast cancer. We believe that strategic educational campaigns to inform the general public and secure their participation in primary and secondary prevention should be founded upon an appreciation of the state of lay public knowledge and

beliefs, accurate or not. Because we intend to design and deliver educational messages to clinical and non-clinical populations in the AOI catchment area in Kenya, using written and spoken content at health centers and local radio stations for reaching the public, having a rich vein of information such as that summarized in Tables 1 and 2 of this paper will be an asset.

Biomedical and epidemiological evidence supports a multitude of risk factors and causes for breast cancer, including genetic endowment, obstetrical and breast feeding history, use of tobacco, low fruit and vegetable dietary intake, lack of exercise and obesity, alcohol intake, and exposure to physical and chemical carcinogens among others[18-20]. By contrast, women in the general Kapsokwony, Mosoriot and Turbo populations have very little knowledge of risk factors for breast cancer and espouse some misconceptions. As others have found, this lack of sound information may adversely affect preventive and curative behaviors[21]. To compound this problematic situation, the women we surveyed in Western Kenya - irrespective of site - perceived breast cancer to be a lethal disease about which little could be done, characterized by symptoms and signs that would be typical only of late-stage cancer. Biomedical treatments, especially surgery, were thought not to be helpful, perhaps dangerous (promoting spread of the cancer) and certainly unaffordable. This kind of mistaken information needs to be remedied to engage the public in our AOI prevention efforts.

This background of popular knowledge is not unique to Kenya. In a Zambian study[22] 82% of rural and 58% of urban women had no knowledge of breast cancer. There is a need for health care workers to deliberately design and promote educational programs to create awareness on the dangers of breast cancer. Notwithstanding the burden of breast cancer in developing countries, these countries have low public awareness of the condition; myths and misconceptions are rampant; and the affected delay initiation of treatment[23-26]. Past research shows that it is common for women in developing countries to be aware of lumps for a long time and not seek care until complications such as pain, ulcer, foul-smelling discharge or symptoms of metastatic disease occur[27-30]. Additionally, the health care work force does not seem to be an active source of breast cancer information. For example, Oluwatosin's[31] (2006) Nigerian study found that the leading source of information about breast cancer was "elders, neighbors and friends" while only 4.4% of the respondents acknowledged health workers as sources of information[31]. It is troubling to find that primary health care workers - who are expected to promote breast cancer awareness - are not the leading source of cancer information.

The important role of mainstream health care providers in patient and public education cannot be overemphasized. There is evidence that some primary health care workers have inadequate knowledge and poor client teaching on early detection of breast cancer.

For instance, only 20% of nurses in a Nigerian teaching hospital considered a painless lump an early sign of breast cancer. Further, 41% considered pain an early sign[32]. The role of health care workers as sources of information and instruction about breast cancer is imperative, for without them, the general population will continue muddling through lay explanatory models instead of gaining factual knowledge about breast cancer causes, risks, symptoms, and management.

Patients must also know more about breast cancer care and what is available. According to KEMRI, about 80% of reported cases of cancer are diagnosed at advanced stages due to the low awareness of cancer signs and symptoms, inadequate screening services, inadequate diagnostic facilities and poorly structured referral facilities[15]. Indeed, research from Kenya shows many with breast cancer symptoms do not seek medical attention until their cancer is very advanced, and knowledge of breast cancer and early detection differentiates with women's social and economic backgrounds[33].

Whatever the context of prevailing popular knowledge, as we seek to promote widespread breast cancer education in our communities, we must remember the role of culture and lay beliefs for they often reflect the framework within which local populations interpret known and emerging diseases. Accordingly, indigenous knowledge should be considered a key element in the development of culturally sensitive breast cancer control and curative programs. Simon[34] (2006) offers four practice principles that can be especially useful when appreciating the role of culture in health behavior: (1) Inclusion and use of indigenous support; (2) Cross-application of approaches for diverse populations; (3) Honor and incorporation of culture; and (4) Paying attention to language, literacy, and cultural information. By so doing, we stand to spur timely diagnosis and associated care uptake in all social contexts[34]. Whatever the accuracy or inaccuracy of common community knowledge about breast cancer, we probably need to use opinions such as those uncovered in this survey as "points of departure" and "information anchors" when seeking to change opinions and advance alternative knowledge.

This study has strengths as well as limitations. It was undertaken in three different regions of Western Kenya and recruited participants from health facilities as well as at the household level in the communities they serve. The participants were thus interviewed at their usual place of residence or familiar environments. The use of a semi-structured tool allowed participants to express their personal perceptions and opinions on the subject matter without restrictions. The utility of open-ended survey questions in such surveys was demonstrated. In general, study participants had very low breast cancer knowledge and wanted to be informed about all types of cancer. Among study limitations, we should first emphasize that Kenya is a melting pot of diverse ethnic cultures and indigenous knowledge and beliefs. This study provides valuable information on lay explanations

of breast cancer but it is not robustly generalizable, even within Kenya. Second, breast cancer rates are on the increase in Kenya, and the role of health workers in breast cancer awareness and care remains only partially explored. The state of breast cancer in the country calls for involvement of all stakeholders, but our study included only lay people and no clinicians, community health workers or health policymakers.

This project reports on lay beliefs about causes, severity, symptoms and treatment of breast cancer in Western Kenya. Lay explanatory models for breast cancer are common and risk factors are not well known in this population. This lack of knowledge has been partly blamed for delay in breast cancer care uptake in Kenya[2]. Development of strategies to spur early detection and enrolment in treatment is critical and should involve health care workers, policy makers and community members at all levels[6]. Organizations such as the Kenya Breast Health Program should be used to educate the public on causal factors, symptoms, and management of breast cancer. Kenyan programs must also build capacity for treating new patients presenting with early-stage disease even as they continue to treat those reporting late with advanced conditions.

The National Cancer Control Strategy - which is based on the World Health Organization's global cancer control strategy - is the first cancer control strategy document to be developed in Kenya. It consolidates aspects in cancer prevention, screening, diagnosis, treatment and care for cancer patients as well as investment needed to deliver these services[15]. This effort is overdue and laudable, but it fails to emphasize the importance of public education in engaging the participation of at-risk populations. With combined efforts that involve international, government, and private partners, a strategy should be pursued that creates breast cancer awareness, in the overall effort to reduce mortality associated with cancer and ensure quality of life for those affected[15].

The role of health care workers in breast cancer education and symptom identification requires attention. Training and research in breast cancer remains a critical need in developing countries whereby available training programs have low levels of funding, suboptimal infrastructure, and continually experience brain drain[6]. In Kenya, although cancer continues to burden many, cancer research is diminutive due to inadequate funding and limited training facilities[15]. Promising areas for future breast cancer work in developing countries include development of training models that can be translated into several languages and applied to diverse cultural settings, and establishment of centers of excellence[6].

COMMENTS

Background
Globally, breast cancer has increasingly become a significant cause of morbidity and mortality in adult populations. This trend has been noted in developing countries like Kenya, where screening, prevention, curative and relevant data systems remain underdeveloped. It is believed in Kenya that levels of

awareness may be low and lay explanatory models for breast cancer persist. The objective of this project was to explore lay perception of causes, severity, presenting symptoms and treatment of breast cancer.

Research frontiers

Approaches are needed to rapidly assess the state of public knowledge to order to tailor health education that might remediate ignorance and misperceptions, especially mis-information that could interfere with timely participation in programs of screening and care. This case report illustrates the use of open-ended questions to assess knowledge of relevance to the early detection of breast cancer.

Innovations and breakthroughs

This case study has unearthed more sheer lack of information and lay misperceptions of how breast cancer presents itself that have been shown to prevail in other settings. The use of open-ended questions permitted a so-called "rapid-ethnographic" approach to characterizing knowledge, one that with the potential to uncover richer information than forced-choice questions.

Applications

Since Kenya has proposed implementing a breast cancer control campaign that lacks a public health education component, the data suggest that such a component may be necessary and could be tailored to remediate apparent deficiencies. Other ministries of health may wish to contemplate the use of open-ended questions to characterize population-based knowledge of chronic diseases that are emerging as major causes of morbidity and mortality.

Terminology

"Open-ended" questions are ones that pose a question but do not force the respondent to choose among limited response options. Open-ended questions require interviewers to record verbatim responses that are subjected to text-based qualitative analysis once compiled. Open-ended questions avoid one disadvantage of forced-choice (multiple choice or single-best answer) questions, which require good knowledge of what the respondent pool will be likely to say about a question *a priori*.

Peer-review

The manuscript by Naanyu *et al* presents an important study exploring breast cancer awareness, knowledge and practices in Western Kenya. According to the results of a survey of people's knowledge and beliefs concerning breast cancer, the authors found significant ignorance and misperceptions. The major limitation of such research is whether its results apply elsewhere. The major strength is illustration of a methodologic approach others may wish to emulate.

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