Understanding Women’s Perspectives on Breast Cancer is essential for cancer control: Knowledge, Risk Awareness, and Care-seeking in Mwanza, Tanzania

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Abstract

Background: Breast Cancer is the most common cancer in women worldwide. Since 2008, Mwanza, Tanzania, has worked to provide comprehensive cancer services through its Zonal consultant hospitals. A new policy focused on clinical breast exam requires that women be aware of and seek care for breast concerns. This new policy necessitates the understanding of community women’s perspectives on breast cancer and care-seeking behavior which are key to successful cancer control.

Methods: A community-based survey was administered to conveniently sampled women aged 30 and older to assess women’s perspectives on breast cancer and care-seeking behavior.

Results: Among 1,129 women with a median age of 37 (IQR: 31-44) years, 73% have heard of cancer and 10% have received breast health education. Women self-evaluated their knowledge of breast cancer (from 1-none to 10-extremely knowledgeable) with a median response of 3 (IQR: 1-4). Only 14% felt they knew any signs or symptoms of breast cancer. Encouragingly, 56% of women were fairly-to-very confident they would notice changes in their breasts, with 24% of women practicing self-breast examination and 21% reporting they had received a past breast exam. Overall, 74% said they would be somewhat-to-very likely to seek care if they noticed breast changes, with 96% noting severity of symptoms as a motivator. However, fear of losing a breast (40%) and fear of a poor diagnosis (38%) were most frequent barriers to care seeking. In assessing knowledge of risk factors, about 50% of women did not know any risk factors for breast cancer whereas 42% of women believed long term contraceptive use a risk factor. However, 37% and 35% of women did not think that family history or being older were risk factors, respectively.

Conclusions: The success of efforts to improve early diagnosis in a setting without
population-based screening depends on women being aware of breast cancer signs and symptoms, risks, and ultimately seeking care for breast concerns. Fortunately, most women said they would seek care if they noticed a change in their breasts, but the low levels of cancer knowledge, symptoms, and common risk factors highlight the need for targeted community education and awareness campaigns.

Background

Breast Cancer is the most common cancer in women worldwide. In high income countries, high visibility public health efforts and advocacy groups have made breast cancer screening programs and education campaigns successful. In low- and middle- income countries (LMICs) incidence and mortality is on the rise and breast cancer is the most common cause of cancer deaths among women. In Tanzania, breast cancer incidence is projected to increase 82% by 2030(1). To combat this, and other cancers, Tanzania has developed guidelines for cancer control and have made efforts to equip major specialty hospitals with diagnostic tools and expanded oncology departments(1, 2).

In Mwanza, Tanzania, Bugando Medical Centre (BMC) serves as the area’s Zonal consultant hospital, with a catchment area of the entire lake region(2) serving over 15 million people(3). In the past ten years, BMC has worked to create, staff and train advanced oncology, surgery, and pathology departments to provide cancer diagnostic, treatment, and radiation services(1). While these services are available, they are underutilized by the general community as women often present to the hospital as late stage or palliative breast cancer cases(4). Late stage presentation--an estimated 80% of all cases--limits women’s options for care and patients cannot take advantage of the full range of treatment options available to them(1). About half of all women diagnosed with breast cancer will die from the disease(1). This trend however is not just common to Tanzania, but to many other LMICs as mortality rates are generally higher than those of high-
income countries (HICs) despite currently lower incidence rates(5, 6).

In Sub Saharan Africa, poor prognosis at diagnosis has been shown to be associated with lower breast cancer awareness and not tumor characteristics alone(6). To understand breast cancer awareness in Mwanza, Tanzania and address women-level barriers to cancer control, we conducted an extensive community-based Knowledge, Attitudes and Practices survey. As Tanzania continues to develop policies and clinical programs to combat the increasing breast cancer incidence, understanding women’s perspectives on breast cancer and care-seeking is fundamental to successful cancer control(7).

Methods

A cross-sectional Knowledge, Attitudes and Practices (KAP) survey was carried out in the Mwanza region of Tanzania. Surveys were administered in Nyamagana, Ilemela and Sengerema which are within the catchment areas of Bugando Medical Centre, the zonal hospital with cancer care capabilities. A convenience sample of women aged 30 or older were recruited by trained, Tanzanian female research staff in public areas such as bus stops, train stops, and open markets in order to enroll general community women. Once eligibility criteria were confirmed, administrators consented participants per IRB requirements and then administered the survey. Consent and the survey were administered in Swahili to ensure widespread understanding. This study was approved by National Institutes for Medical Research, Tanzania (NIMR), the Catholic University of Health and Allied Sciences-Bugando Medical Centre (CUHAS-BMC), and from Johns Hopkins Bloomberg School of Public Health (JHSPH).

Survey Development and Administration

The core of the KAP survey was based on the Breast Cancer Awareness Measures (BCAM) (8) developed by Cancer Research UK. This series of questionnaires were developed to
specifically assess cancer awareness in the general population and are tailored to specific cancers(8). In the field, the BCAM has demonstrated high construct validity as well as readability(9, 10), and has successfully been used in East Africa(11). Additional questions were added to the subset of selected BCAM questions in order to meet the study objectives and best adapted to the local context. Our KAP survey included sections on population demographics, self-reported cancer awareness, familiarity of cancer and knowledge of symptoms, confidence, skills and behavior about changes in the breasts, previous contact with the health system regarding breast health, barriers to care, knowledge of risk factors, and questions about breast cancer specifically in Tanzania. Knowledge of breast cancer symptoms was assessed twice, once by asking if women knew any symptoms and if yes, then recording those they recalled. Next, all women were read a list of symptoms and asked to indicate those they recognized as symptoms. To ensure appropriate use of language and translation, the survey was fully developed in English then translated to Swahili using a native Tanzanian Swahili speaker. The translated survey was then back translated into English by a different native Tanzanian Swahili speaker to check for consistency. Any inconsistencies were worked out between the Principal investigator (A.F. Rositch) and the two translators to maintain question integrity. The survey was programmed into Qualtrics Survey Software (Qualtrics, Provo, UT) and downloaded onto password protected tablets to be utilized in the field. Experienced survey administrators were trained on proper use of tablets and Qualtrics survey, consent procedures, and consistent language and approach to asking survey questions. The survey was pilot tested prior to roll out for training purposes and to ensure a culturally appropriate language and understanding. Survey responses were entered directly into Qualtrics in real-time by the interviewer and then uploaded to the secure server at a later time. This allowed women to be surveyed anywhere, while increasing
Data security and minimizing data loss. Data was output directly from Qualtrics, where it was quality checked, translated into English, and free text was cleaned and categorized (if applicable).

Data and Analysis

We assessed knowledge of breast cancer through a series of questions about breast cancer symptoms, survival, risk factors or statistics. Risk Awareness was assessed through questions that specifically asked the woman’s perspective on her own body, chances of developing breast cancer and familial history of breast cancer. Attitudes and practices around breast cancer and care-seeking were assessed through questions pertaining to behaviors, potential barriers, experience with the healthcare system and likelihood of care seeking. Descriptive statistics (frequencies, proportions, and mean/medians) were used to describe the population demographics, basic breast cancer knowledge, and risk factor awareness. Data on barriers and motivators of care-seeking are visually displayed.

Analysis of Variance (ANOVA) was used to estimate and compare mean knowledge scores between demographic, risk, and care-seeking variables and both self-reported knowledge and a built knowledge score. The Tukey Test was used to determine subgroups with significantly different knowledge levels, with alpha=0.05. Self-reported knowledge was measured directly on the survey by asking women to rate their knowledge of breast cancer on a scale of 1-10. The built knowledge score was calculated based on knowledge of risk factors and knowledge of symptoms or signs, with a maximum score of 12.5. For each known risk factor (from Table 3), 1 point was awarded to the score. Women were also awarded 1 point if they simply indicated that they knew signs and symptoms of breast cancer (from Table 3); they earned 0.25 for each specific sign or symptom they free listed or indicated knowing when read off to them. Women were also awarded 1 point for understanding the importance of early detection (from Table 2). The self-reported score
and the knowledge-built score were both converted to percentages (0-100%) for analysis and comparability. Data were analyzed using Stata 12.1 (StataCorp, College Station, TX).

Results

A total of 1129 women were enrolled and completed the survey. The median age of women was 37 (IQR 31-45), and the majority of women were married (62.7%) and identified as Christian (73.6%) [Table 1]. Access to transportation was limited with only 8.4% of women indicating they had access to a personal car or van and 6.9% indicating they had access to a motorcycle. The majority of women completed some formal education (65.3%; equivalent to primary school in the United States) and very few (7.0%) had school at the university/college level or beyond. Only 21.4% of women reported having health insurance and almost all women reported visiting a traditional healer in the past (85.5%).

Most women indicated that they had heard of cancer (73.9%), and 10.4% reported they had received previous breast cancer education [Table 2]. A quarter of women said they know someone (family or otherwise) who has or had breast cancer, and 2.7% reported they had been diagnosed with breast cancer themselves. On a scale from 1-10, women self-rated their knowledge of breast cancer to be very low (Median 3; IQR: 1-4). Of the 155 women who said that they knew breast cancer symptoms (13.7%), a lump or thickening in the breast (69.8%) or under the armpit (75.5%) were the most common free-listed symptoms. Other top responses included pain in the breasts or armpit (49.7%), nipple rash (46.4%) and discharge or bleeding from the nipple (43.9%). The most commonly known symptoms among all women when they were read-off were, similarly, a lump or thickening in the breast (36.4%) or under the armpit (34.8%), pain in the breasts or armpit (34.2%) and discharge or bleeding from the nipple (32.6%).

Risk factors awareness was assessed by asking women to rate their agreement on a series of statements [Table 3]. Some risk factors got lukewarm responses, such as “Being
overweight (BMI over 25) can increase the chance of getting breast cancer” and “Mutations in your genes (BRAC1 or BRAC2) can increase the chance of getting breast cancer” with about 50.0% of women indicating that they were “not sure” and about 25.0% of women either agreeing or disagreeing. Notably, 41.6% of women agree that long term contraceptive use is a risk factor for breast cancer. Women did not think that family history or being older were risk factors, with 15.1% and 14.6% agreement, respectively. When women were asked to list any other risk factors they knew or believed to be causes of breast cancer, responding women (n=84) often referred to food, clothing, and traditional healers or drugs as being risk factors. Examples of food-related responses included drinking processed juices or soda, eating foods from plastic containers, excessive alcohol consumption and diet in general. Pertaining to clothing, women believed that wearing dirty or wet clothes, tight bras, and secondhand clothes were risk factors. Additionally, storing money or cell phones in the bra, and wearing black bras in the sun were listed as risk factors. Vaccinations by a traditional healer, using traditional medicine for a long time, using drugs without a Medical Doctors approval, and using drugs to enlarge breasts were also believed to be risk factors for breast cancer. Most women couldn’t gage their own chances of developing breast cancer, with 53.5% of women reporting they were unsure of their lifetime risk of breast cancer. Fortunately, the majority of women agreed that early detection is important (72.3%), it is possible to treat breast cancer (69.7%), and that treatment is available to them in Mwanza (58.3%). Care-seeking practices around breast health were very limited, with 21.7% of participants reporting that they have ever been checked for any type of cancer [Table 4]. Specifically, 12.8% reported having ever had a clinical breast exam (CBE) and 5.2% reported either having a mammogram or ultrasound. Only 23.6% of women reported self-examining their breasts before, although most women indicated they were very confident (16.3%) or fairly
confident (39.4%) they would notice a change in their breast. If women noticed a change in their breasts, the majority of women said they were very (25.3%) or somewhat likely (47.2%) to seek care, and that the first place they would go is the district hospital (66.1%) as opposed to a community health clinic (31.7%) or traditional healer (2.2%).

Of all the assessed barriers to care seeking for breast concerns, women overwhelmingly answered “yes, often” or “yes sometimes” such that the combined responses were at least 95% for each barrier. The three items that women most commonly reported “often” as barriers to care-seeking were fear of losing a breast (40.0%), being worried about what might be found (37.9%), and difficulty arranging transportation (35.3%) [Figure 1]. The three least chosen barriers were being too embarrassed (24.8%), having too many things to worry about (24.2%), and their husband disapproving (23.0%). On the other hand, the items that women said would motivate them to seek care for a breast concern were severity of the symptoms and concern (97.0%) of women reporting, if they knew more about breast issues and breast cancer (69.0%), and if they had support from their partner or family (53.0%) [Figure 2]. Having the clinic closer/easier to attend and if they weren’t so busy or had childcare were least likely to impact their care seeking behaviors.

The average built knowledge score was 24.5% (STD=0.6) and the self-reported knowledge average was 17.2% (STD=0.5). The built score increased with age up to age 49 whereas there was no difference in women’s self-reported knowledge by age [Table 5]. Rural populations comparatively knew less about breast cancer than urban populations as measured by both the built (-21%) and self-reported (-4.5%) knowledge scores. There was variability by marital status, and Muslim women tended to have slightly higher built and self-reported knowledge scores compared to Christian women. University educated women scored the highest by both knowledge measures (32.0% built and 28.5% self) but interestingly, women who reported being unsure of highest completed school level or
having no schooling scored significantly higher than women with a “class-level” (P = 0.011) and “form-level” education (P = 0.000) (corresponding to the primary school and middle/high school in the United States respectively) on the built knowledge score. Not surprisingly, women who reported having received prior breast health/cancer education scored higher than women without this education (35.1% vs. 23.2% built and 27.5% vs. 15.9% self). On the other hand, women who have done a breast self-exam had slightly lower knowledge scores compared to women who haven’t done self-exams. In summary, urban dwelling women, those with an occupation classified as profession or manual labor, those with University of higher education, and those with prior breast health education tended to have both the highest built knowledge score (>30%) and self-reported knowledge (>20%).

Discussion

In Tanzania, breast cancer is the second leading cancer in both incidence and mortality among women, with an estimation of 3037 new cases and 1303 deaths in 2018, and is expected to increase to more than 120% for both incidence and mortality by the year 2040(1, 12). As a country, Tanzania is relatively new to adopt cancer control programs and invest in community cancer services(2). This study illustrates the need to factor in women’s perspectives when considering cancer control programs and the strength in conducting knowledge assessments. We did this survey in order to influence future breast cancer control efforts in the lake zone catchment area. In our study, women did not know common risk factors for developing breast cancer such as family history and being older. However, the majority of women did understand that early detection is important to surviving breast cancer, that it is possible to treat breast cancer, and that treatment is available to them in Mwanza. While it is positive that women know breast cancer is treatable, less than one sixth of women indicated they knew any signs or symptoms of
breast cancer at all and yet nearly all women would be likely to seek care only if their symptoms were severe. They also indicated numerous barriers they face when care-seeking which is concerning as the National Breast Cancer Control strategy hinges on women recognizing symptoms early and presenting at a health center to obtain a clinical breast examination (CBE) for their breast concern(13). Other findings had a more positive outlook as over half of women said they would first seek care for breast concerns at a hospital, as compared to a traditional healer, and that they would like to know more about breast cancer. The results of this study demonstrate a clear need for continuing assessments of women’s knowledge and perspectives and offers a starting point for breast cancer educational campaigns to accompany clinical programs for early detection. 

Not surprisingly, community women do not have a comprehensive understanding of breast cancer. The majority of women indicated that they had heard of breast cancer and could identify at least breast or armpit lumps as symptoms but very few women had received any breast cancer education previously. This is not uncommon in East Africa, with surveys in coastal and Western Kenya reporting similar results(14, 15). In another Tanzanian study based in Dar es Salaam, 70.2% of women looking for outpatient care at the district hospital recognized breast lump successfully(16). In a survey among 230 Nigerian women, only 50% of the women noted a painless lump as the breast cancer symptom(17). Similarly, in a large survey assessing the perceptions of breast cancer among non-healthcare personnel in Kenya only around 12% recognized breast lump as a symptom and less than 2% recognized breast rash, and changes in the nipple as signs and symptoms(14). This is also true of risk factor knowledge. Of the women surveyed, very few agreed that being older or having a close relative with breast cancer can increase the chance of getting breast cancer. In a study from Western Kenya, 52.5% of those surveyed did not know any breast cancer risk factors and only 12.3% mentioned heredity(14).
Comparatively, in the study of Nigerian women, around 45% and 33% thought family history and old age were breast cancer risk factors, respectively(17). For cancer control programs to be successful at detecting breast cancer early, especially programs that rely on women taking the initiative to seek care, community women must possess the bare minimum knowledge of breast cancer signs, symptoms and risk factors.

General barriers to care seeking specifically for a breast concern were overwhelming. Of each presented barrier, fear of losing their breast was the common response. This sentiment is likely reflective of the current method of treatment, as surgery is generally the first and most common procedure, and breast-conserving/breast-sparing options are nascent in many LMIC settings(1, 18). Similar research has explored the idea of prioritizing responsibility for other family members needs over the woman’s own(19, 20) and this is also reflective in our research as majority of women were worried about what might be found in a medical exam and only present when their symptoms are severe and presumably interfere with everyday life. Studies have acknowledged that low awareness of breast cancer symptoms may prevent women from noticing, and even misinterpret or ignore these symptoms, which contribute to the delay of women’s presentation in the hospital and subsequent diagnosis(14, 21). For example, when women had detected lumps, they may still wait until the appearance of other symptoms, such as pain, before turning to medical help(14). Almost all women in our study indicated that they would be motivated to seek care if their symptoms were severe. This is worrisome that severity of symptoms is a motivator since it is the opposite of cancer controls “early detection” goal. Late presentation, diagnosis, and treatment have been serious challenges for breast cancer control in many other LMICs, but elevated breast cancer awareness has shown to be associated with higher breast self-examination practice frequency, screening participation, earlier presentation, and better follow-up to referral and treatment(6, 9, 19,
Looking at overall knowledge, women do not believe they know a lot about breast cancer and did not demonstrate high health awareness of breast cancer. Groups that typically knew less about breast cancer were from rural areas, tended to be younger and identified their occupation as ‘peasant’. Our study revealed that previous health related education or university level education, were both factors for high built knowledge scores. However, the level of education received did not affect women’s breast cancer awareness significantly. This finding was consistent with a study in China(26), but deviates from other studies in Nigeria(27), Pakistan(28), and Saudi Arabia(29), which reported a potentially positive relationship between education level and breast cancer awareness. Several retrospective studies have shown the importance of breast health awareness and early presentation as they positively impact survival(30-32). When developing health education programs it is important to target groups that both need education and can share and disseminate knowledge to peers and other community members(33, 34). Religious outreach campaigns can utilize the community aspect of religion to target and recruit participants(35). In addition, several studies have acknowledged the impact of religion on breast cancer control, and suggest incorporating a component of religion when developing health education programs(36, 37). Educational campaigns at schools similarly can easily recruit participants and the knowledge learned while young will follow a woman through her life arming her with the necessary tools to recognize suspicious symptoms and seek care sooner(38).

Moving forward, this initial study gives clear guidance on where basic pitfalls exist regarding community knowledge and barriers to care. Strengths of this study include the large sample size and distribution of women all over Mwanza. Our population was also not limited to women already in a healthcare setting. We sampled women from public areas
where people congregate, and this made our study population more representative of the
general population and our results generalizable for the lake region. In addition, we
adapted a well validated and widely used instrument to assess breast cancer awareness,
ensuring comparability with other studies. As this is a good initial assessment of
knowledge and practices, further assessments into care seeking and beliefs are necessary
to explore the topics of care seeking motivations and barriers further. Further qualitative
assessments would allow us to better characterize true barriers to knowledge and care-
seeking and develop targeted, evidence-informed interventions.

Conclusions

The Tanzania guidelines hinge on women seeking care for breast concerns. When women
are delayed or do not understand the significance of their symptoms they will present
later, which limits treatment options and decreases breast cancer survival. These
shortfalls in basic breast cancer facts can be targets for future education campaigns and
can point to informing dissemination strategies. Our study found that women believed if
they knew more about breast health and breast cancer, they would be more motivated to
seek care for breast concerns and they also indicated they would seek care in a hospital
setting first for these concerns. This finding illustrates the community’s desire for more
knowledge and sets up future campaigns for success, as women should be more receptive
to learning. The Tanzanian National guidelines focused on CBE should be coupled with
clear dissemination strategies that include community awareness and education of women
to promote care-seeking. At the current capacity, breast cancer treatment is most
effective for women who present early and this would ensure program success. As our
study shows, there are still a multitude of barriers that women face when pressed with
care seeking and the top two indicated barriers deal with fear of the diagnosis and
treatment itself. Education focused on the whole cancer care continuum are imperative for
women to understand the outcomes of early presentation as they compare to late presentation and the availability of treatment to her. Community involvement is critical to successful cancer control. As Tanzania and other countries continue to build their cancer treatment capacity, so should they build up their outreach and community education capacity.

**Abbreviations**

LMIC: low- and middle- income countries

HIC: High-income countries

BMC: Bugando Medical Centre

KAP: Knowledge, Attitudes and Practices

NIMR: National Institutes for Medical Research, Tanzania

CUHAS - BMC: Catholic University of Health and Allied Sciences-Bugando Medical Centre

JHSPH: Johns Hopkins Bloomberg School of Public Health

BCAM: Breast Cancer Awareness Measures

ANOVA: Analysis of Variance

BMI: Body Mass Index

CBE: Clinical Breast Exam

**Declarations**

**Ethics Approval and Consent to participate**

This study was approved by National Institutes for Medical Research, Tanzania (NIMR), the Catholic University of Health and Allied Sciences-Bugando Medical Centre (CUHAS-BMC), and by Johns Hopkins Bloomberg School of Public Health (JHSPH). Written consent was obtained by trained study staff prior to survey initiation. Both consent and survey were administered in Swahili to ensure widespread understanding.
Consent for Publication

Not applicable.

Availability of data and materials

The dataset analyzed in the current study is not publicly available due to ongoing analysis and manuscript creation but requests for research collaboration using the data may be submitted to the corresponding author.

Competing interests

The authors declare that they have no competing interests.

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Authors’ contributions

AFR was responsible for conception of the study, study design, study implementation, and was a major contributor in writing the manuscript. KV and KM contributed to the study design and provided site specific guidance. LH performed data analysis and contributed to the writing of the manuscript. CC contributed to study design, study implementation, performed the data analysis and drafted the manuscript. All authors read and approved the final manuscript.

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Tables

Table 1. Demographics of 1,1290 participants in the KAP survey in the Lake Zone of Tanzania

| Age, median (IQR) | 37 (31-45) |
|-------------------|------------|
| Age Categories    |            |
| 30-39             | 635 (56.2%)|
| 40-49             | 293 (26.0%)|
| 50-59             | 163 (14.4%)|
| 60-69             | 28 (2.5%)  |
| 70+               | 10 (0.9%)  |
| Region            |            |
| Urban             | 304 (26.9%)|
| Peri Urban        | 419 (37.1%)|
| Rural             | 406 (36.0%)|
| Marriage          |            |
| Married           | 708 (62.7%)|
| Not married       | 330 (29.2%)|
| Divorced or Separated | 91 (8.1%) |
| Religion          |            |
| Christianity      | 831 (73.6%)|
| Muslim            | 297 (26.3%)|
| Table 2. Breast Cancer Knowledge and Risk Awareness of women in the community |
|---|
| **Living arrangement** | **Other** | **1 (0.1%)** |
| Rent from NHC | **34 (3.0%)** | |
| Rent from private landlord | **774 (68.5%)** | |
| Own outright or have a mortgage | **309 (27.4%)** | |
| Other or Don't know | **12 (1.1%)** | |
| **Transportation** | **No transportation** | **907 (80.3%)** |
| Access to Bicycle | **49 (4.4%)** | |
| Access to Motorcycle | **78 (6.9%)** | |
| Access to car or Van | **95 (8.4%)** | |
| **Occupation** | **Peasant** | **209 (18.5%)** |
| Business | **748 (66.3%)** | |
| Manual labor | **88 (7.8%)** | |
| Professional | **58 (5.1%)** | |
| Other | **26 (2.3%)** | |
| **Highest education received** | **No schooling or Don't know** | **143 (12.7%)** |
| Up to Class | **737 (65.3%)** | |
| Up to Form | **170 (15.0%)** | |
| University and Post University | **79 (7.0%)** | |
| **Health Insurance** | **Yes** | **242 (21.4%)** |
| No or Don't know | **887 (78.6%)** | |
| **Ever visited a Traditional Healer** | **Yes** | **965 (85.5%)** |
| No | **164 (14.5%)** | |
| Have you ever heard of cancer? | Response | N (%) |
|--------------------------------|----------|-------|
| Yes                           | 834      | (73.9%) |
| No                            | 295      | (26.1%) |

| Have you ever received previous education about breast health or breast cancer? | Response | N (%) |
|-----------------------------------------------------------------------------|----------|-------|
| Yes                                                                         | 119      | (10.5%) |
| No                                                                          | 1010     | (89.5%) |

| Do you know anyone, family or otherwise, who has been diagnosed with breast cancer? | Response | N (%) |
|-----------------------------------------------------------------------------|----------|-------|
| Yes                                                                         | 293      | (26.0%) |
| No                                                                          | 836      | (74.0%) |

| Have you ever been told that you have breast cancer? | Response | N (%) |
|-----------------------------------------------------|----------|-------|
| Yes                                                  | 30       | (2.7%) |
| No                                                   | 1099     | (97.3%) |

| On a scale from 1-10 how would you rate your knowledge of breast cancer? | median (IQR) |
|------------------------------------------------------------------------|---------------|
|                                                                        | 3 (1-4)       |

| Do you know any of the warning signs or symptoms of breast cancer? | Response | N (%) |
|------------------------------------------------------------------|----------|-------|
| Yes                                                              | 155      | (13.7%) |
| No                                                               | 974      | (86.3%) |

| Symptoms                                                         | Free listed* | Read off** |
|------------------------------------------------------------------|--------------|------------|
|                                                                  | N = 155      | N=1129     |
| Change in position of the nipple                                  | 32 (20.6%)   | 89 (57.4%) | 291 (25.8%) |
| Puckering or Dimpling of the breast skin                         | 35 (22.6%)   | 91 (58.7%) | 308 (27.3%) |
| Nipple rash                                                      | 72 (46.4%)   | 116 (74.8%)| 360 (31.9%) |
| A lump or thickening under the armpit                             | 117 (75.5%)  | 122 (78.7%)| 393 (34.8%) |
| Pulling in of the nipple                                          | 58 (37.4%)   | 106 (68.4%)| 347 (30.7%) |
| Discharge or bleeding from the nipple                             | 68 (43.9%)   | 111 (71.6%)| 368 (32.6%) |
| Redness of the Breast skin                                       | 36 (23.2%)   | 87 (56.1%) | 322 (28.5%) |
| Changes in the shape of the breast or nipple                      | 35 (22.6%)   | 89 (57.4%) | 336 (29.8%) |
| Pain in one of the breasts or armpits                            | 77 (49.7%)   | 111 (71.6%)| 386 (34.2%) |
| A lump or thickening in the breast                               | 108 (69.8%)  | 124 (80.0%)| 411 (36.4%) |
| Changes in the size of the breast or nipple                      | 31 (20.6%)   | 88 (56.8%) | 307 (27.2%) |

*Free listed: If women indicated that they knew any of the signs or symptoms of breast cancer they were then asked to verbally list the ones they knew. These were captured and recorded. **Read off: Once women were done free listing OR if they did not know any signs or symptoms of breast cancer, they were then read this list of signs and symptoms and asked to indicate which ones they believed were true.

Table 3. Knowledge of Breast Cancer Risk Factors of KAP participants
| Topic                                                                 | Disagree | Not Sure | Agree |
|----------------------------------------------------------------------|----------|----------|-------|
| Being older can increase the chance of getting breast cancer         | 399 (35.3%) | 565 (50.1%) | 165 (14.6%) |
| Not breastfeeding can increase the chance of getting breast cancer   | 211 (18.7%) | 600 (53.1%) | 318 (28.2%) |
| Having a close relative with breast cancer can increase the chance of getting breast cancer | 414 (36.7%) | 544 (48.2%) | 171 (15.1%) |
| Long term hormone contraceptive use can increase the chance of getting breast cancer | 145 (12.9%) | 514 (45.5%) | 470 (41.6%) |
| Being overweight (BMI over 25) can increase the chance of getting breast cancer | 244 (21.6%) | 650 (57.6%) | 235 (20.8%) |
| Do you know any other risk factors?                                  | Yes 84 (7.4%) |
| If Yes,                                                              |          |
| Of or pertaining to food or drink†                                   | 34 (40.5%) |
| Traditional Healer/Traditional drugs‡                                | 16 (19.0%) |
| Of or pertaining to Bras and Clothes§                                | 12 (14.3%) |
| Other                                                                | 22 (26.2%) |
| What do you think your own chances are to develop breast cancer in your lifetime? |          |
| Likely                                                               | 145 (12.8%) |
| Moderate                                                             | 273 (24.2%) |
| Unlikely                                                             | 107 (9.5%)  |
| Don’t know                                                           | 604 (53.5%) |
| Early detection is important to surviving breast cancer              |          |
| Disagree                                                             | 14 (1.2%)  |
| Not Sure                                                             | 299 (26.5%) |
| Agree                                                                | 816 (72.3%) |
| It is possible to treat breast cancer                               |          |
| Disagree                                                             | 43 (3.8%)  |
| Not Sure                                                             | 299 (26.5%) |
| Agree                                                                | 787 (69.7%) |
| There is treatment available for you to treat breast cancer in Mwanza? |          |
| Disagree                                                             | 63 (5.6%)  |
| Not Sure                                                             | 408 (36.1%) |
| Agree                                                                | 658 (58.3%) |

†Examples include: Food in general, Drinking Juice or Soda, Eating food from plastic containers, excessive alcohol consumption. ‡Examples include: Being vaccinated by a traditional healer, using traditional medicine for a long time, using drugs without a Medical Doctors approval, using drugs to enlarge breasts. §Examples include: Wearing secondhand clothes, wearing dirty or wet clothes, wearing a tight bra, wearing a black bra in the hot sun, keeping money in the bra.
### Table 4. Breast Cancer Practices and Care seeking behavior of KAP participants

|                                                | Response | N (%)  |
|------------------------------------------------|----------|--------|
| Have you ever been checked for cancer?         | Yes      | 245 (21.7%) |
|                                                | No       | 884 (78.3%) |
| Have you ever had a clinical breast exam (CBE)?| Yes      | 144 (12.8%) |
|                                                | No       | 985 (87.2%) |
| Have you ever had any other type of breast exam (mammogram or ultrasound?) | Yes | 59 (5.2%) |
|                                                | No       | 1070 (94.8%) |
| Have you ever examined your breasts yourself to feel for any lumps or cancer (SBE)? | Yes | 266 (23.6%) |
|                                                | No       | 863 (76.4%) |
| If yes, how often do you check your breasts?   | At least once a week | 76 (28.6%) |
|                                                | At least once a month | 23 (8.6%) |
|                                                | At least once every 6 months | 13 (4.9%) |
|                                                | Rarely or Never | 154 (57.9%) |
| Are you confident you would notice a change in your breasts? | Very Confident | 184 (16.3%) |
|                                                | Fairly Confident | 445 (39.4%) |
|                                                | Slightly Confident | 154 (13.7%) |
|                                                | Not at all Confident | 296 (26.2%) |
|                                                | Don’t know | 50 (4.4%) |
| If you noticed changes in your breasts how likely are you to seek care? | Very likely | 286 (25.3%) |
|                                                | Somewhat likely | 533 (47.2%) |
|                                                | Not Sure | 101 (9.0%) |
|                                                | Somewhat unlikely | 79 (7.0%) |
|                                                | Very unlikely | 130 (11.5%) |
| If you had a question about your breast or noticed a lump or a change in your breasts, where is the first place you would go to get care? | Traditional healer | 25 (2.2%) |
|                                                | Community health clinic | 358 (31.7%) |
|                                                | District Hospital | 746 (66.1%) |

### Table 5. Factors associated with self-reported knowledge of breast cancer and a built knowledge score based on KAP survey responses
| Scores range 0 - 100% | Mean (%) | Comparisons ± STD | P-value | Mean (%) |
|-----------------------|----------|--------------------|---------|----------|
| Age                   |          |                    |         |          |
| 30-34                 | 20.7     | REF                |         | 15.7     |
| 35-39                 | 27.2     | 6.5 ± 1.8          | 0.003   | 18.2     |
| 40-44                 | 29.0     | 8.2 ± 1.8          | 0.000   | 18.4     |
| 45-49                 | 28.5     | 7.7 ± 2.0          | 0.001   | 16.7     |
| 50+                   | 24.3     | 3.5 ± 1.7          | 0.231   | 18.7     |
| Region                |          |                    |         |          |
| Urban                 | 33.1     | REF                |         | 20.4     |
| Peri Urban            | 30.4     | -2.7 ± 1.4         | 0.121   | 16.0     |
| Rural                 | 11.9     | -21.1 ± 1.4        | 0.000   | 15.9     |
| Marriage              |          |                    |         |          |
| Single                | 22.3     | REF                |         | 18.6     |
| Married               | 26.3     | 4.0 ± 1.3          | 0.008   | 17.1     |
| Divorced/Separated    | 17.9     | -4.4 ± 2.4         | 0.160   | 12.0     |
| Religion              |          |                    |         |          |
| Christian             | 23.8     | REF                |         | 16.2     |
| Muslim                | 26.4     | 2.6 ± 1.4          | 0.055   | 19.8     |
| Occupation            |          |                    |         |          |
| Peasant               | 19.8     | REF                |         | 18.3     |
| Business              | 23.4     | 3.6 ± 1.5          | 0.135   | 15.1     |
| Manual Labor          | 38.4     | 18.7 ± 2.5         | 0.000   | 26.1     |
| Professional          | 34.6     | 14.8 ± 2.9         | 0.000   | 25.9     |
| Other                 | 23.7     | 3.9 ± 4.1          | 0.877   | 15.4     |
| Highest Education     |          |                    |         |          |
| No school/Don’t know  | 29.5     | REF                |         | 17.6     |
| Class 4 or 7/8        | 23.9     | -5.7 ± 1.8         | 0.011   | 16.0     |
| Form 4 or 6           | 19.4     | -10.1 ± 2.3        | 0.000   | 16.4     |
| University and Beyond | 32.0     | 2.5 ± 2.8          | 0.816   | 28.5     |
| Ever received breast health or breast cancer education | No/Don’t know | 23.2 | REF | 15.9 |
| | Yes | 35.1 | 11.9 ± 2.0 | 0.000 |
| Have you ever heard of cancer | No/Don’t know | 14.5 | REF | 14.4 |
| | Yes | 28.0 | 13.6 ± 1.3 | 0.000 |
| Family or friend, who has been diagnosed with breast cancer | No/Don’t know | 24.7 | REF | 17.1 |
| | Yes | 23.8 | -0.9 ± 1.4 | 0.498 |
| Have you ever done breast self-exam | No/Don’t know | 24.9 | REF | 18.7 |
| | Yes | 23.3 | -1.6 ± 1.4 | 0.271 |

All the numbers in Table 5 were on percentage scale (0-100%), except for P value; STD=standard deviation.
**Figures**

**Figure 1**

Barriers to care-seeking for breast concerns among community women. *This graph represents only the “yes, often” responses.
Motivating factors for breast concern care-seeking among KAP participants.

*Women were asked if each of these factors would make them more likely to seek care for a breast concern. **1% of women also stated that “Advice from a Medical Specialist” would be a motivation for care seeking.