original report abstract

Establishing Cohorts to Generate the Evidence Base to Reduce the Burden of Breast Cancer in Sub-Saharan Africa: Results From a Feasibility Study in Kenya

Sujha Subramanian, PhD[1]; Robai Gakunga, MPH[2]; Madeleine D. Jones[1]; Asaph Kinyanjui, MBChB[3]; Emily Ochieng'[4]; Nancy Gikaara[3]; Florence Maluni[4]; David Wata, MPharm[5]; Anne Korir, MPH[6]; Miriam Mutebi, MMed Surg[7]; and Zipporah Ali, MD, MPH, MPC[3]

PURPOSE By 2025, Kenya is estimated to experience a two-thirds increase in the incidence of breast cancer. Local research is necessary to generate evidence to inform policy, public health, and medical practice. There have been no longitudinal cohort studies in sub-Saharan Africa of women with and without breast cancer. Our aim is to assess the feasibility of conducting cohort studies in Kenya that consider clinical characteristics, socioeconomic factors, and self-care behaviors.

METHODS We initiated a short-term follow-up cohort study of women with and without a diagnosis of breast cancer with baseline face-to-face data collection and one follow-up interview (at approximately 3 months by telephone). We developed tailored instruments to capture demographics, socioeconomic factors, breast cancer risk, ability to identify breast cancer symptoms, treatments received for breast cancer, and quality of life of survivors.

RESULTS We recruited 800 women between the ages of 20 and 60 years and successfully collected baseline data. Completeness of the data was high for demographic variables, but there was a larger proportion of missing information for specific variables required for assessing breast cancer risk. Respondents were able to complete standardized instruments to assess breast cancer knowledge among those without breast cancer and identification of symptoms among survivors. We were able to successfully contact approximately 80% of the participants for follow-up.

CONCLUSION This short-term follow-up study provides evidence that women can be successfully tracked and contacted for follow-up in the Kenyan setting and offers lessons to establish future longitudinal cohorts to identify approaches to improve breast cancer outcomes.

J Global Oncol. © 2019 by American Society of Clinical Oncology

Creative Commons Attribution Non-Commercial No Derivatives 4.0 License

INTRODUCTION

Breast cancer incidence is expected to increase substantially in sub-Saharan Africa, and the mortality rate among those diagnosed with breast cancer is much higher in sub-Saharan Africa than in high-resource settings.[1-3] The breast cancer incidence rate in Kenya is estimated at 38.3 per 100,000 women, and the mortality rate is 17.3 per 100,000 women.[1] In the United States, the breast cancer incidence rate is much higher, whereas the mortality rate is much lower (0.09% and 0.01%, respectively).[4] Furthermore, women are diagnosed with breast cancer at a younger age in Kenya, with a median age of approximately 49 years, compared with a median age of 62 years in the United States.[2,5]

The anticipated growth in breast cancer incidence in countries such as Kenya is fueled by multiple interrelated factors including demographics, lifestyle, genetics, and the environment. The Kenya National Cancer Control Strategy (2017 to 2022) identified several priority research areas, including research on behavioral factors, environmental and occupational risk factors, and treatment options, including their effectiveness and costs.[6] Although breast cancer research in Kenya is providing useful insights, studies are often limited to specific medical institutions and usually involve small numbers of patients.[7-10] Large-scale, community-based patient cohorts are crucial to provide findings on disease presentation, treatment outcomes, and survivorship experiences.

In this article, we report findings on the feasibility to initiate and conduct cohort studies to address key research questions to improve breast cancer care in Kenya. Our objectives were to understand barriers related to recruitment, evaluate the ability to collect high-quality baseline data to address research gaps related to screening and treatment, and assess

ASSOCIATED CONTENT

Appendix

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on February 5, 2019 and published at ascopubs.org/journal/jgo on March 25, 2019: DOI https://doi.org/10.1200/JGO.18.00225

whether we could contact patients for follow-up. Findings from this study can provide important lessons to tailor future longitudinal studies to the local environment to ensure successful recruitment and long-term follow-up.

METHODS

We conducted a feasibility study to inform best practices for initiating longitudinal cohort studies in Kenya. We collected baseline data using face-to-face interviews and collected follow-up data via telephone approximately 3 months later. The study included women age 20 to 60 years with and without a diagnosis of breast cancer in separate cohorts. We selected this age range to include both women with a high incidence of breast cancer and those eligible for screening. We limited inclusion in the breast cancer cohort to those who were diagnosed within the past 3 years (measured at the time of survey administration). We aimed to recruit 400 women in each cohort from four counties in Kenya, Nairobi, Kiambu, Machakos, and Nyeri, to ensure adequate representation of women who live in urban and rural counties.

We collected data including patient demographics, socioeconomic factors, risk factors, breast cancer treatment methods, and insurance status (Appendix Table A1). Previously validated instruments and tools were used to collect details on breast cancer risk and knowledge.[11-14] The questionnaire was initially developed in English and then translated into Kiswahili. Cognitive testing was performed (40 women) to assess the reliability and validity of the questionnaires.

Ethical approval for this study was obtained from the Kenyatta National Hospital–University of Nairobi Ethics and Research Committee and the RTI International Institutional Review Board. We recruited women diagnosed with breast cancer through the membership lists maintained by the Kenya Cancer Association and the Kenya Hospices and Palliative Care Association. We also recruited survivors of breast cancer from Kenyatta National Hospital (the main referral hospital in Kenya) and health care facilities and breast cancer survivorship groups in the targeted counties. The cohort of women without breast cancer were recruited through the membership lists of the Kenya Cancer Association and the Kenya Hospices and Palliative Care Association, from health care facilities, and through general outreach in the community. After eligibility assessment, trained research assistants helped the women who met the recruitment criteria to provide written informed consent to participate in the baseline and follow-up assessments. We included women who voluntarily gave consent. We excluded women who did not speak and understand the study languages (English and Kiswahili) and those who were unable to provide contact information for themselves and next of kin. Face-to-face interviews were held either at the same location on the same day of recruitment or at a later time or day by appointment; consent was obtained immediately before the interview. Participants received a copy of the consent form and were offered nominal financial support for interview-related expenses including travel (up to approximately $5). The initial face-to-face data collection was followed by a one-time follow-up interview by telephone approximately 3 months after baseline. Women were recruited for the baseline interview between November 2017 and April 2018, and all follow-up telephone interviews were completed by July 2018.

We began performing data processing and analysis in the field by evaluating data completeness and ensuring quality control. Hard copies of data from paper instruments were then entered into an electronic database with only a study-assigned identifier to ensure patient anonymity. Additional checks were conducted to identify missing values, out-of-range inputs, and validity of the survey skip patterns. Queries were resolved by reviewing the paper records. Data on women with and without breast cancer are presented separately to reflect their distinct groups. Our goal was not to compare the two cohorts but to learn about the experiences of these women to inform screening, diagnosis, and treatment of breast cancer. We present descriptive statistics on demographics, socioeconomic factors, insurance, employment status, comorbidities, and treatment of breast cancer. We collected information on a wide range of comorbidities, including cardiovascular conditions, depression, and weight issues. To facilitate analyses, we developed a summary measure of the total number of conditions reported. We also present summary measures for some of the key variables that are required to generate breast cancer risk scores.[15,16] For each variable, we report the proportion of missing values to highlight the completeness of the information available for analysis. We present this information for both cohorts to evaluate the ability to collect this information from women in Kenya.

For women without a breast cancer diagnosis, we present the level of breast cancer knowledge by analyzing the concepts in the Breast Cancer Awareness Measure (BCAM). In addition, we explored the quality of life among survivors of breast cancer using the standardized scoring algorithm for the Functional Assessment of Cancer Therapy–Breast Cancer Symptom Index-16 (FBSI-16; Version 2). The FSBI-16 contains 16 response items for which respondents select one response from the following five available options: “not at all,” “a little bit,” “somewhat,” “quite a bit,” and “very much.” On the basis of how an item is phrased, we either report the percentage who responded “not at all” and “a little bit” or “quite a bit” and “very much.” To assess our ability to re-establish contact with participants to conduct longitudinal studies in the future, we report the percentage of women in both cohorts who participated in the follow-up telephone interviews. We assigned those with whom we were unable to follow up to one of the following six categories: died during follow-up period, refused or unavailable for follow-up interview,

 © 2019 by American Society of Clinical Oncology

TABLE 1. Demographic Characteristics by Survey Cohort

	Women With Breast Cancer (n = 400)		Women Without Breast Cancer (n = 400)	
Characteristic	**No.**	**%**	**No.**	**%**
Age, years, mean*	46.1		39.2	
Place of residence				
Nairobi, Mombasa, other cities	125	31.3	82	20.5
Other towns	70	17.5	54	13.5
Countryside	204	51.0	261	65.3
Outside Kenya	1	0.3	2	0.5
Missing	0	0.0	1	0.3
Educational attainment				
None	10	2.5	6	1.5
Primary	136	34.0	101	25.3
Secondary/vocational	149	37.3	154	38.5
College	70	17.5	109	27.3
University	33	8.3	26	6.5
Missing	2	0.5	4	1.0
Marital status				
Never married	41	10.3	79	19.8
Married/living together	244	61.0	226	56.5
Divorced/separated	68	17.0	63	15.8
Widowed	46	11.5	30	7.5
Missing	1	0.3	2	0.5
Religion				
Roman Catholic	112	28.0	117	29.3
Protestant/other Christian	281	70.3	270	67.5
Muslim	6	1.5	8	2.0
Other	0	0.0	3	0.8
Missing	1	0.3	2	0.5
Employment status				
Employed or working for pay	132	33.0	258	64.5
Unemployed; plan to seek employment	134	33.5	86	21.5
Unemployed; do not plan to seek employment	127	31.8	49	12.3
Missing	7	1.8	7	1.8
Type of insurance coverage (multiple plans allowed; not mutually exclusive)				
None	119	29.8	199	49.8
National Hospital Insurance Fund	268	67.0	187	46.8
Private insurance	50	12.5	38	9.5
No. of comorbid conditions or ailments				
Mean	1.60		0.75	
0	22	5.5	211	52.8
1-2	320	80.0	164	41.0
3-4	46	11.5	23	5.8
> 5	12	3.0	2	0.5

NOTE. All values are numbers and percentages, unless noted otherwise.

*Age was missing for four women with breast cancer and one woman without breast cancer.

problem communicating, hospitalized as a result of an illness, traveling and cannot be reached, or other reason including could not be reached by telephone.

RESULTS

We successfully recruited 800 women, and as shown in Table 1, the level of completeness was high across all demographic variables, with missing values of 2% or less. The average age of the women in our study was 46 years for women with breast cancer and 39 years for those without a diagnosis of breast cancer. The majority of the participants in both cohorts indicated they were from the countryside; the next most frequently cited locations were major cities such as Nairobi and Mombasa. The most common level of educational attainment for both groups was secondary or vocational school (women with breast cancer, 37.3%; women without cancer, 38.5%), followed by primary school for women with breast cancer (34.0%) and college for women without breast cancer (27.3%). Most of the participants in both cohorts were married and considered themselves to be Protestants. Women without breast cancer were twice as likely to be used (64.5%) compared with women with breast cancer (33.0%), although approximately one third of these survivors planned to pursue employment in the future. Nearly 70% of women with breast cancer had insurance compared with approximately half of the women without breast cancer. The mean number of comorbid conditions was 1.60 for women with breast cancer and 0.75 for those without breast cancer. The vast majority of women with breast cancer reported one to two comorbid conditions (80.0%), and most participants without breast cancer (52.8%) did not report any conditions.

TABLE 2. Frequency Distribution of Breast Cancer Risk Assessment Characteristics

Characteristic	Women With Breast Cancer (n = 400)		Women Without Breast Cancer (n = 400)	
	No.	%	No.	%
Age, years				
Mean	46.1		39.2	
< 45	187	46.8	307	76.8
≥ 45	209	52.3	92	23.0
Missing	4	1.0	1	0.3
No. of first-degree relatives with breast cancer				
0	327	81.8	351	87.8
1	66	16.5	43	10.8
≥ 2	4	1.0	2	0.5
Missing	3	0.8	4	1.0
No. of breast biopsies				
0	187	46.8	380	95.0
1	121	30.3	1	0.3
≥ 2	85	21.3	0	0.0
Missing	7	1.8	15	3.8
Age at menarche, years				
≥ 14	257	64.3	276	69.0
12-13	84	21.0	94	23.5
< 12	8	2.0	7	1.8
Did not know	49	12.3	18	4.5
Missing	2	0.5	5	1.3
Age at first live birth, years				
No live births	19	4.8	40	10.0
< 20	95	23.8	105	26.3
20-24	170	42.5	169	42.3
25-29	84	21.0	61	15.3
≥ 30	29	7.3	22	5.5
Missing	3	0.8	3	0.8

NOTE. All values are numbers and percentages, unless noted otherwise.

In Table 2, we report the descriptive statistics of some of the key variables that are required to generate breast cancer risk scores. We present data for women with and without breast cancer to assess availability of the data elements; we do acknowledge that risk assessment for breast cancer is not relevant to those already diagnosed with breast cancer. Current age, first-degree relative with breast cancer, and age at first birth were generally complete, with less than 1% of values missing for both cohorts. As expected, many more women with breast cancer reported undergoing biopsies than women without breast cancer; however, 3.8% of women without breast cancer did not respond to this question. There were also barriers to complete data collection for first menstruation (ie, menarche). Overall, 12.3% of women with breast cancer did not know their age at menarche, as opposed to 4.5% of those without breast cancer.

Figure 1 presents results from the BCAM that was administered to women without breast cancer to ascertain their knowledge of breast cancer warning signs, symptoms, and risk factors. The vast majority of participants (81.5%) identified a lump in the breast as a warning sign of breast cancer, followed by discharge from the nipple (75.3%), bleeding from the nipple (74.5%), and dimpling of the breast skin (60.8%). Conversely, the symptoms that were least often cited were a nipple rash (42.0%), the nipple pulling inward (40.0%), and change in nipple position (36.5%). As shown, a plurality of participants (36.8%) reported checking their breasts every week; however, the second most common response was “rarely or never” (33.0%). Furthermore, more than three fifths of women without breast cancer (63.6%) reported feeling “very confident” or “fairly confident” in their ability to detect such a change.

In Table 3, we report on the clinical and treatment-related variables pertaining to women with breast cancer. The most

 © 2019 by American Society of Clinical Oncology

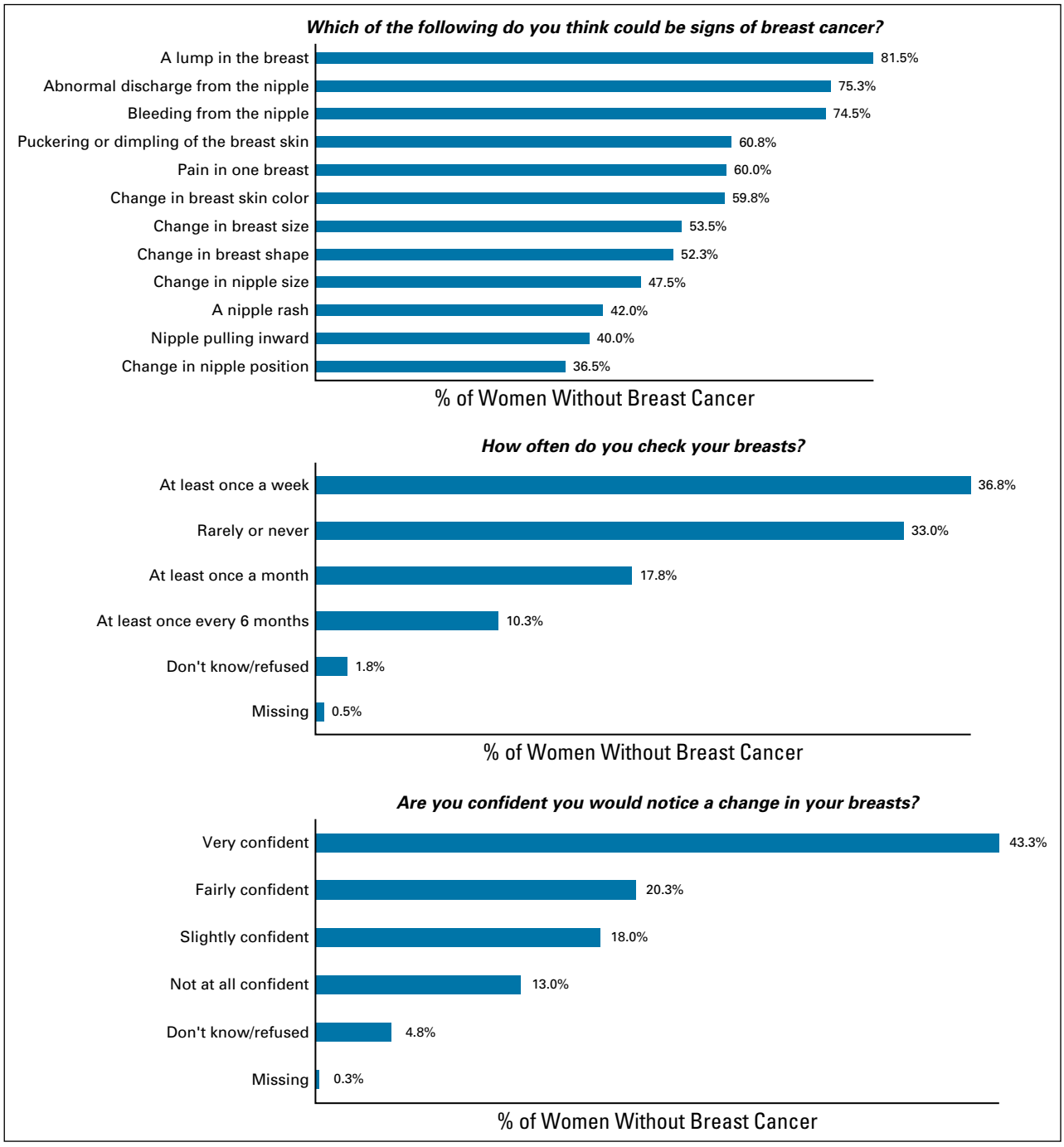

FIG 1. Responses to the Breast Cancer Awareness Measure.

common disease stages at diagnosis were stage II (39.5%) and stage III (30.3%); 11.8% of women could not identify their stage. Almost 80% of women with breast cancer were still in treatment at the time of the survey administration. The vast majority of women (93.0%) had received chemotherapy, and other commonly cited tests and treatments were mastectomy (74.5%) and radiotherapy (53.0%). Among those who knew their receptor status, the most common were human epidermal growth factor receptor 2 positive (14.8%) and endocrine receptor positive (8.3%). More than two thirds of the women with breast cancer (68.7%) did not know their receptor status. The mean FBSI-16 score among our study participants was 19.2 (Fig 2). In the context of the FBSI-16, a patient who scores 0 is severely symptomatic, and a patient who scores 64 is asymptomatic. The most commonly cited FBSI-16 symptom or consequence of breast cancer was the inability to work (37.9%) or to meet the needs of the family (35.9%). Approximately one fourth of women also reported that they experience pain and fatigue "quite a bit" or "very much."

TABLE 3. Treatment-Related Outcomes Among Women Without Breast Cancer

Outcome	Women With Breast Cancer (n = 400) No.	%
Breast cancer stage at diagnosis		
0	10	2.5
I	31	7.7
II	158	39.4
III	121	30.2
IV	30	7.5
Did not know	47	11.7
Missing	3	0.8
Elapsed time since last cancer treatment		
I am still receiving treatment	319	79.6
< 1 year ago	29	7.2
1 year ago to < 2 years ago	21	5.2
> 2 years ago	20	5.0
I have not been treated for cancer	8	2.0
Missing	3	0.8
Breast cancer treatments and procedures		
Chemotherapy	373	93.0
Radiotherapy	212	52.9
Surgery-mastectomy	298	74.3
Breast reconstruction	14	3.5
Hormonal therapy	109	27.2
Immunotherapy	45	11.2
Bone-directed therapy	15	3.7
Physical therapy	36	9.0
Breast cancer receptor status		
Endocrine receptor (estrogen or progesterone receptor)–positive breast cancer	33	8.3
HER2-positive breast cancer	59	14.8
Triple negative, not positive to receptors for estrogen	21	5.3
Triple negative, positive to receptors for estrogen	10	2.5
Inflammatory breast cancer	2	0.5
Did not know	275	68.7

Abbreviation: HER2, human epidermal growth factor receptor 2.

Table 4 lists the results from our follow-up survey. We were able to contact 87.8% of the participants with breast cancer or their next of kin for follow-up and 79.0% of the participants without breast cancer approximately 3 months after our initial baseline data collection. The most common reason we were unable to contact participants in the breast cancer cohort was because they had died (4.8%). For women without breast cancer, the most frequent reason was general refusal (11.5%). This code covered responses ranging from "refused to answer questions" to "too busy during the day to take calls."

DISCUSSION

We conducted this short follow-up prospective cohort study of women with and without a diagnosis of breast cancer in Kenya to evaluate the approach of using face-to-face interviews and follow-up telephone calls to collect longitudinal data. We were able to successfully enroll our target of 400 women per cohort and collected baseline information for all participants. Data completeness was high for demographic variables, and women were able to describe their experiences with both breast cancer screening and treatment. Most of the women were also able to provide details on data elements required for breast cancer risk assessment; however, there was a large proportion of missing information for age of menarche. This data element was not available in approximately 6% of women without breast cancer and in a much higher rate of up to 13% among women with breast cancer. Survivors of breast cancer were substantially older (52% were age 45 years or older) than the women without a cancer diagnosis (23% were age 45 years or older), and there were also some differences in education level and area of residence, which may have influenced the variation seen across these two cohorts. Furthermore, more than two thirds of the women reported that they did not know their receptor status; it is unclear whether they either did not recall being tested or had not been tested. The reasons for missing or unknown data should be additionally evaluated in future studies. In this study, we attempted to collect key variables related to breast cancer risk, and in follow-up studies, we can expand to include a broader range of factors including the use of hormonal contraceptives in Kenya.

Our findings are also encouraging because women were able to provide the information required for the standardized items included in the BCAM and the FBSI-16. These results support prior research that also validated the use of the BCAM to assess breast cancer knowledge and barriers among Kenyan women.[17] Many of the women without a diagnosis of breast cancer were generally aware of the symptoms of breast cancer—especially common symptoms such as a lump, abnormal discharge, and bleeding—but less than half were aware of the risk posed by other symptoms such as change in nipple size and position. Importantly, approximately 20% of these women were unaware that the presence of a lump in the breast could be indicative of breast cancer. This lack of universal knowledge clearly highlights the need for additional education and awareness of breast cancer symptoms. Although more than half of the women interviewed reported performing breast self-exams at least monthly and the majority were confident in their ability to identify breast changes, we are unable to assess the actual skill and reliability of the women's self-assessment. A longitudinal follow-up study

 © 2019 by American Society of Clinical Oncology

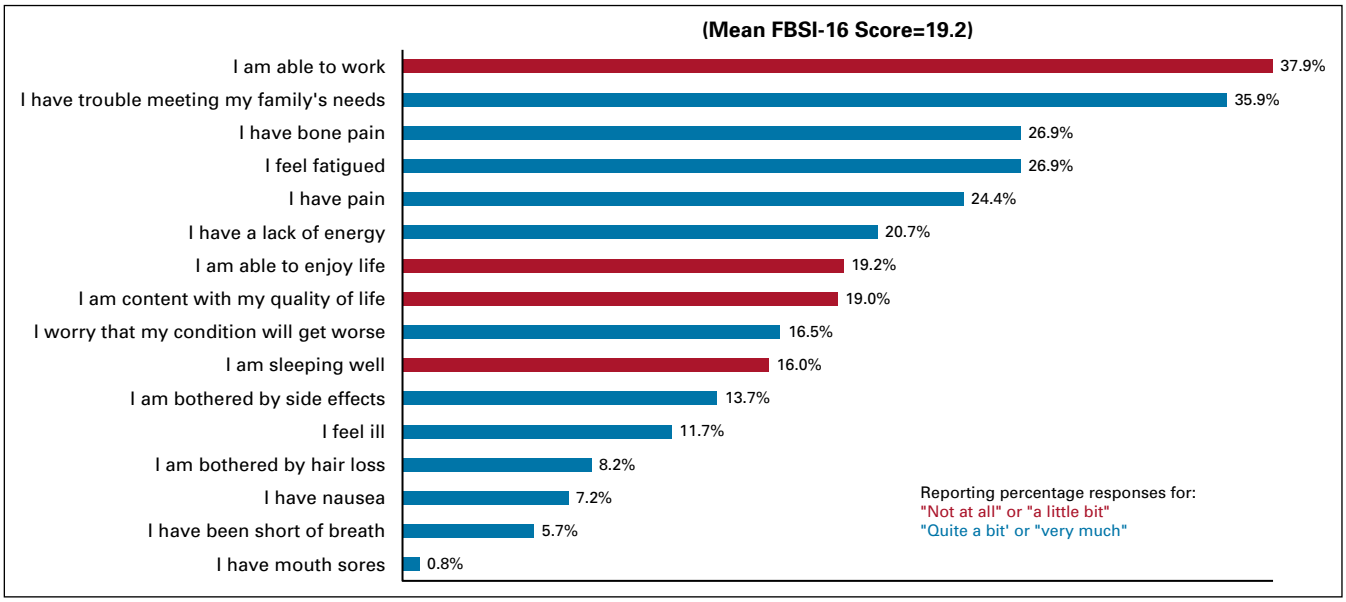

FIG 2. Functional Assessment of Cancer Therapy–Breast Cancer Symptom Index-16 (FBSI-16) mean score and response items.

will be required to systematically monitor and assess women's behavior and ability to identify breast cancer to reduce the frequency of late-stage presentation of patients with breast cancer that currently exists in Kenya.[18] Similarly, additional research is also required to explore the findings from the FBSI-16 assessment. Women with breast cancer experience a range of issues during and after treatment, and their inability to work and care for their families could be minimized by optimal interventions and support systems to improve their quality of life.

There is limited research on cohort studies, and longitudinal cohorts have not been previously established in Kenya and many other sub-Saharan African countries because of their high cost and challenges in maintaining participant contact.[19-21] With increased mobile technology, we presume that continued contact with participants during a study period is feasible and can be accomplished in a more cost-effective manner than previously possible.[22,23] We were able to successfully recontact a large proportion of the participants in both cohorts of this study (88% of the women with breast cancer and 79% of those without breast cancer). We were unable to reach approximately 5% of the breast cancer cohort despite multiple attempts to contact the patients as well as next of kin by telephone. In the future, we suggest collecting provider information (physician name or hospital) to improve the follow-up rate and to identify the women's status. Among those who participated in the cohort without a diagnosis of breast cancer, almost

TABLE 4. Response to Follow-Up Telephone Interview

	Women With Breast Cancer (n = 400)		Women Without Breast Cancer (n = 400)	
Response	**No.**	**%**	**No.**	**%**
Participant responded to follow-up telephone interview	351	87.8	316	79.0
Participant responded	345	86.3	316	79.0
Next of kin responded	6	1.5	0	0.0
Reason participant was not interviewed				
Died during follow-up period (eg, died of meningitis)	19	4.8	2	0.5
Refused or unavailable for follow-up interview (eg, reached but refused to talk)	4	1.0	46	11.5
Problem communicating (eg, difficulty speaking as a result of cough)	3	0.8	3	0.8
Hospitalized as a result on an illness (eg, currently sick in the hospital)			3	0.8
Traveling and cannot be reached (eg, out of the country)	4	1.0	2	0.5
Other reasons including cannot be reached by telephone (eg, technical issues, did not respond)	19	4.8	28	7.0

12% refused the follow-up interview when contacted by telephone. Anecdotal evidence gained by the interviewers suggests that these women were not willing to engage in long-term follow-up because they did not see themselves as sick. Lack of awareness of breast cancer risk and stigma associated with breast cancer may limit women's willingness to participate in cohort studies, especially those without a breast cancer diagnosis.[24] Therefore, appropriate tools and approaches are required to communicate the research procedures along with the benefits and potential drawbacks of participating in longitudinal cohort studies.

A key strength of this study is that we were able to collect detailed information from 800 women to identify barriers to breast cancer screening and treatment to reduce the burden from this disease among Kenyan women. Although we were able to show that many important data elements can be collected, the quality of this information was not assessed. For instance, there could be response bias because women may have provided socially or personally desirable answers, such as indicating that they were very confident in identifying breast cancer signs and symptoms. In addition, women's responses can be subject to recall bias, especially for treatment responses if breast cancer treatment occurred several years before the study interviews. In the future, we could request approval from participants to access medical records pertaining to their breast cancer treatment so clinical data are available to evaluate completeness and accuracy of patient-reported risk factors and treatment modalities. In addition, all women who participated in this cohort study were identified from the regions within or in close proximity to Nairobi county, and therefore, our findings may not be generalizable to the entire country.

The findings from this study can offer important lessons for future cohort studies in Kenya and other sub-Saharan African countries. Our feasibility study of 800 participants with short-term follow-up provides the evidence that women can be tracked and contacted to initiate longitudinal cohort studies. Local evidence on breast cancer prevention, screening, and treatment is critical for tailored interventions to address the growing burden of breast cancer in sub-Saharan African countries.

AFFILIATIONS

[1]RTI International, Research Triangle Park, NC
[2]Independent Research Scientist, Nairobi, Kenya
[3]Kenya Hospices and Palliative Care Association, Nairobi, Kenya
[4]Kenya Cancer Association, Nairobi, Kenya
[5]Kenyatta National Hospital, Nairobi, Kenya
[6]Kenya Medical Research Institute, Nairobi, Kenya
[7]Aga Khan University, Nairobi, Kenya

CORRESPONDING AUTHOR

Sujha Subramanian, PhD, RTI International, 3040 E Cornwallis Rd, PO Box 12194, Research Triangle Park, NC 27709; e-mail:ssubramanian@rti.org.

SUPPORT

Supported by RTI International.

AUTHOR CONTRIBUTIONS

Conception and design: Sujha Subramanian, Robai Gakunga, Asaph Kinyanjui, Nancy Gikaara, Zipporah Ali

Administrative support: Emily Ochieng', Nancy Gikaara, Florence Maluni, Zipporah Ali

Provision of study materials or patients: Emily Ochieng', Anne Korir

Collection and assembly of data: Sujha Subramanian, Robai Gakunga, Madeleine D. Jones, Asaph Kinyanjui, Emily Ochieng', Nancy Gikaara, Florence Maluni, Zipporah Ali

Data analysis and interpretation: Sujha Subramanian, Robai Gakunga, Madeleine D. Jones, Asaph Kinyanjui, Nancy Gikaara, David Wata, Anne Korir, Miriam Mutebi, Zipporah Ali

Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/jco/site/ifc.

Madeleine D. Jones
Employment: Epic Systems Corporation (I)

David Wata
Honoraria: Novartis, GlaxoSmithKline
Travel, Accommodations, Expenses: Janssen Oncology

No other potential conflicts of interest were reported.

ACKNOWLEDGMENT

We acknowledge Kenya Hospices and Palliative Care Association, its membership, and its affiliated palliative care units and the Kenya Cancer Association, its membership, and its affiliated support groups.

REFERENCES

1. International Agency for Research on Cancer: GLOBOCAN: Global Cancer Observatory. http://gco.iarc.fr/
2. Korir A, Okerosi N, Ronoh V, et al: Incidence of cancer in Nairobi, Kenya (2004-2008). Int J Cancer 137:2053-2059, 2015
3. Kisiangani J, Baliddawa J, Marinda P, et al: Determinants of breast cancer early detection for cues to expanded control and care: The lived experiences among women from western Kenya. BMC Womens Health 18:81, 2018
4. National Institutes of Health: National Cancer Institute: Surveillance, Epidemiology, and End Results Programme. Cancer stat facts: Female breast cancer. https://seer.cancer.gov/statfacts/html/breast.html

 © 2019 by American Society of Clinical Oncology

5. Sawe RT, Kerper M, Badve S, et al: Aggressive breast cancer in western Kenya has early onset, high proliferation, and immune cell infiltration. BMC Cancer 16:204, 2016
6. Kenya Ministry of Health: National Cancer Control Strategy 2017-2022. http://kehpca.org/wp-content/uploads/KENYA-NATIONAL-CANCER-CONTROL-STRATEGY-2017-2022.pdf
7. Nkonge KM, Rogena EA, Walong EO, et al: Cytological evaluation of breast lesions in symptomatic patients presenting to Kenyatta National Hospital, Kenya: A retrospective study. BMC Womens Health 15:118, 2015
8. Kiarie GW, Abinya NO, Joshi MD, et al: Familial clustering of cancer in two tertiary care hospitals in Nairobi, Kenya. East Afr Med J 87:9-13, 2010
9. Shaikh AJ, Mullooly M, Sayed S, et al: Mammographic breast density and breast cancer molecular subtypes: The Kenyan-African aspect. Biomed Res Int 2018:6026315, 2018
10. Sayed S, Moloo Z, Wasike R, et al: Ethnicity and breast cancer characteristics in Kenya. Breast Cancer Res Treat 167:425-437, 2018
11. Kenya National Bureau of Statistics: Kenya demographic and health survey 2014. https://dhsprogram.com/pubs/pdf/fr308/fr308.pdf
12. National Cancer Institute: Breast Cancer Risk Assessment Tool. https://bcrisktool.cancer.gov/
13. Linsell L, Forbes LJ, Burgess C, et al: Validation of a measurement tool to assess awareness of breast cancer. Eur J Cancer 46:1374-1381, 2010
14. Facit.org: Questionnaires. http://www.facit.org/facitorg/questionnaires
15. Gail MH, Costantino JP, Pee D, et al: Projecting individualized absolute invasive breast cancer risk in African American women. J Natl Cancer Inst 99:1782-1792, 2007
16. Gail MH, Brinton LA, Byar DP, et al: Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. J Natl Cancer Inst 81:1879-1886, 1989
17. Wachira J, Busakhala A, Chite F, et al: Refining a questionnaire to assess breast cancer knowledge and barriers to screening in Kenya: Psychometric assessment of the BCAM. BMC Health Serv Res 17:110, 2017
18. Otieno ES, Micheni JN, Kimende SK, et al: Delayed presentation of breast cancer patients. East Afr Med J 87:147-150, 2010
19. Cubasch H, Dickens C, Joffe M, et al: Breast cancer survival in Soweto, Johannesburg, South Africa: A receptor-defined cohort of women diagnosed from 2009 to 11. Cancer Epidemiol 52:120-127, 2018
20. Effi AB, Aman NA, Koui BS, et al: Immunohistochemical determination of estrogen and progesterone receptors in breast cancer: Relationship with clinicopathologic factors in 302 patients in Ivory Coast. BMC Cancer 17:115, 2017
21. Kantelhardt EJ, Zerche P, Mathewos A, et al: Breast cancer survival in Ethiopia: A cohort study of 1,070 women. Int J Cancer 135:702-709, 2014
22. Holmes MD, Dalal S, Volmink J, et al: Non-communicable diseases in sub-Saharan Africa: The case for cohort studies. PLoS Med 7:e1000244, 2010
23. Dalal S, Holmes MD, Laurence C, et al: Feasibility of a large cohort study in sub-Saharan Africa assessed through a four-country study. Glob Health Action 8:27422, 2015
24. Busakhala NW, Chite FA, Wachira J, et al: Screening by clinical breast examination in Western Kenya: Who comes? J Glob Oncol 2:114-122, 2016

APPENDIX

TABLE A1. Kenya Breast Cancer Cohort Study: Components of the Questionnaire

Components	Cohort		Source of Questions
	Women With Breast Cancer	Women Without Breast Cancer	
Background information: demographics, socioeconomic status, health status	√	√	Kenya Demographic and Health Survey (2014)[11]
Breast cancer risk assessment	√	√	Breast Cancer Risk Assessment Tool–US National Cancer Institute, https://bcrisktool.cancer.gov[12]
Insurance status and employment	√	√	Investigator-developed questions
Breast cancer knowledge		√	Breast Cancer Awareness Measure Toolkit Updated September 2, 2011 (Modified)[13]
Breast cancer symptom assessment	√		Investigator-developed questions and the National Comprehensive Cancer Network Functional Assessment of Cancer Therapy–Breast Cancer Symptom Index-16 (Version 2), http://www.facit.org/facitorg/questionnaires[14]
Qualitative feedback: questions to obtain suggestions on how to improve self-care behaviors and health care delivery	√	√	Investigator-developed questions

 © 2019 by American Society of Clinical Oncology