



## Financial barriers related to breast cancer screening and treatment: A cross-sectional survey of women in Kenya



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### ABSTRACT

**Background:** Breast cancer is a leading cause of cancer mortality among women in Kenya. Regular screening and optimal treatments can reduce the burden from this disease, but the cost of health care is a barrier to accessing these services. The objective of this study is to assess barriers to breast cancer screening and treatment services, with special emphasis on economic aspects.

**Methods:** We recruited 400 women with and 400 women without a diagnosis of breast cancer and conducted face-to-face interviews. We developed tailored instruments to capture demographics, socioeconomic factors, employment status, insurance coverage, barriers to seeking care, and treatment cost. Qualitative feedback was also sought from the participants.

**Results:** Among women without breast cancer, the most commonly cited impediments to receiving medical care were cost (46.3 %) and transportation (23.3 %). For women with breast cancer, 53.8 % reported that they had to forego care because of cost and 91.2 % reported that their diagnosis impacted household financial wellbeing. Additionally, about half the women (44.9 %) with insurance coverage indicated that the reimbursement received for medical costs was less than they expected to receive.

**Conclusion:** For women both with and without diagnosed breast cancer, cost was a major concern in seeking medical services. Affordability and access to breast cancer screening and treatment need to be improved. Providing more comprehensive insurance coverage is a key solution.

### 1. Introduction

Breast cancer is a leading cause of cancer mortality among women in Kenya and a substantial contributor to early mortality [1,2]. By 2025, the annual incidence of breast cancer in Kenya is predicted to increase to 7396 (66 % increase), with an annual mortality of 3258 people [3]. Women are diagnosed with breast cancer at a younger age in Kenya with a median age at diagnosis of about 49 years versus 62 years in the United States [2,4]. Diagnosis at younger ages adds to the burden experienced by all members of the family. More than two-thirds

of breast cancer cases in Kenya are diagnosed at a late stage, when treatments are less effective and have substantial morbidity impacts [5,6].

Breast cancer treatments are expensive and, even with insurance coverage, many households incur high household debt and deterioration of financial wellbeing. Studies across the globe have documented the economic burden resulting from lost productivity, medical costs, and the lasting effects of treatments that affect the quality of life and financial wellbeing of cancer survivors. [7–12] Breast cancer survivors are more likely to report inability to work and have more employment

**Abbreviations:** BCAM, Breast Cancer Awareness Measure; KEHPCA, Kenya Hospices and Palliative Care Association; KENCANSA, Kenya Cancer Association; KES, Kenyan shillings; NHIF, National Hospital Insurance Fund; USD, U.S. dollars

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disability, including reduced job hours or taking more leave time due to ill health [13–16]. These detrimental outcomes have substantial negative consequences—not only for the women diagnosed with breast cancer but for society as a whole, due to reduced productivity and premature mortality.

Studies specific to Kenya indicate that the cost of medical care is extremely high relative to the average income. [17] A recent costing analysis reported that while public-sector patient cost for treating stage I, II, and III breast cancer ranged from \$1340.38 to \$1542.58, costs in the private sector ranged from \$10,915 to \$11,862 [18]. The payments required for breast cancer treatment, even in the lower-cost public sector, are beyond the reach of the average Kenyan, as the annual household expenditure per adult is about \$413 [19]. Many Kenyans currently health insurance coverage through the National Hospital Insurance Fund (NHIF), but not all costs related to diagnosis and follow-up care are included in the breast cancer treatment package. Additionally, substantial nonmedical costs can be incurred related to breast cancer treatment and management, including the cost of transportation [20]. These costs, when compounded with the loss of income due to the inability to stay employed, can result in catastrophic household financial burden resulting from breast cancer treatment or symptoms.

In the Kenyan setting, the types of impacts of these financial barriers on breast cancer care as well as the magnitude of the impacts are not known. Information is lacking on the extent to which cost is a barrier to health-seeking behavior related to screening and treatment, both of which are essential to reduce the economic burden from cancer. Screening is essential to facilitate early stage diagnosis, along with optimal cancer treatment and survivorship care, to reduce premature mortality. The objective of this study is to assess barriers to breast cancer screening and treatment services, with special emphasis on economic aspects. The findings from this study can assist in formulating policies and interventions in Kenya and other Sub-Saharan African countries to improve breast cancer outcomes and reduce the financial burden of the disease.

## 2. Methods

### 2.1. Study design and cohort participants

The study included women age 20–60 with and without a diagnosis of breast cancer in separate cohorts. This age range was selected to include women with a high incidence of breast cancer, those in the 40–60-year age range, [2,3] and younger women who are recommended to undergo breast screening via clinical breast exams or mammograms. Furthermore, in the breast cancer cohort, we limited inclusion to those who were diagnosed within the past 3 years (measured at the time of the survey administration). We aimed to recruit 400 women in each cohort, 800 women in total, to allow for a sample size capable of addressing the study objectives. The women without breast cancer were recruited to identify barriers related to seeking screening and diagnostic testing to ensure that breast cancers can be diagnosed at an early stage while those with breast cancer were recruited to understand barriers in seeking and receiving optimal treatment. We selected four counties in Kenya—Nairobi, Kiambu, Machakos, and Nyeri.

### 2.2. Questionnaire development

Table 1 summarizes the components included in the baseline questionnaires and provides details on the source of the questions. We reviewed published literature on key concepts and solicited expert opinion to further tailor the content for the Kenyan setting. The data collected included patient demographics, socioeconomic, risk factors, and breast cancer treatment and insurance status. Previously validated instruments and tools were used to collect details on breast cancer risk, breast cancer knowledge, and barriers to seeking care. During the

follow-up telephone interview, we collected detailed qualitative feedback on patient experiences. The questionnaire was initially developed in English and then translated into Kiswahili. The translation was conducted using the well-established approach of forward-translation and then back-translation to ensure that the intent and meaning of the questions were accurately captured.

Cognitive testing was performed to assess the reliability and validity of the questionnaires. We conducted one-on-one interviews lasting about 60 min each with 40 women and ensured equal representation of women with and without breast cancer. Half the women were selected to conduct cognitive testing in English and the other half reviewed questionnaires in Kiswahili. The cognitive testing helped assess the clarity of the questions and the ability of the interviewees to understand and provide accurate responses. Participants were instructed to listen to each question and then convey to the interviewer which response or responses applied and justify the selection of their response, so that comprehension could be assessed. Following the completion of the questionnaire, the interviewer probed the respondent on any aspects of the questionnaire that proved difficult or confusing. We also queried the participants to obtain additional details on the length and burden of the questions, and their feelings about the content of the questions. The findings from the cognitive testing were used to tailor the wording in the questionnaires to reduce any ambiguity.

### 2.3. Cohort recruitment

Ethical approval for this study was obtained from the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee and the Research Triangle Institute (RTI) International Independent Review Board. We recruited women diagnosed with breast cancer through the membership lists maintained by partner organizations, Kenya Cancer Association (KENCANSA) and Kenya Hospices and Palliative Care Association (KEHPCA); these organizations provide navigation services and palliative care services to cancer patients. We also recruited breast cancer survivors from Kenyatta National Hospital (the main referral hospital in Kenya) and health care facilities and breast cancer survivorship groups in the targeted counties. The women not diagnosed with breast cancer were recruited through the membership lists of KENCANSA and KEHPCA, the health care facilities, and general outreach in the community.

After eligibility assessment, trained research assistants helped consecutive women meeting the recruitment criteria to provide written informed consent to participate in the baseline and follow-up assessment. The present study was embedded within a short-term follow-up cohort study so the criteria for recruitment was based on the overall study objectives. We included women who voluntarily gave consent and were able to provide contact information for themselves and next of kin so that we could conduct the follow-up telephone interviews. We excluded women who did not speak and understand the study languages, English and Kiswahili. Face-to-face interviews were held either at the same location on the day of recruitment or at a later time or day with an appointment; in each case, consent was obtained immediately before the interview. Participants were given a copy of the consent form and offered nominal financial support for travel and expenses related to the interview (about \$5). The results presented in this study are drawn from the initial face-to-face data collection that was undertaken with all women who provided consent. The women were recruited for the baseline interview from November 2017 to April 2018, and all follow-up telephone interviews were completed by July 2018.

### 2.4. Data analysis

Data processing and analysis began in the field by checking for completeness of the data and performing quality control checks. Information collected in paper instruments was then entered into an electronic database, which included only study assigned identifiers to

**Table 1**  
Kenya Breast Cancer Cohort Study - Components of the Questionnaire.

Components	Cohort		Source of questions
	Women with breast cancer	Women without breast cancer	
Background Information To collect details such as (1) demographics, (2) socioeconomic status, (3) health status	√	√	Kenya Demographic and Health Survey (2014) [21]
Breast Cancer Risk Assessment Insurance status and Employment	√	√	Breast Cancer Risk Assessment Tool – US National Cancer Institute <a href="https://www.cancer.gov/bcrisktool/">https://www.cancer.gov/bcrisktool/</a> [22]
Breast Cancer Knowledge Breast cancer symptom assessment	√	√	Investigator developed questions Breast Cancer Awareness Measure (BCAM) Toolkit Updated 09.02.11 (Modified) [23]
Qualitative feedback. Questions to obtain suggestions on how to improve self-care behaviors and health care delivery	√	√	Investigator developed questions and the NCCN FBSI-16 (Version 2) ( <a href="http://www.facit.org/facitorg/questionnaires">http://www.facit.org/facitorg/questionnaires</a> ) [24]

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 rechecking the paper records. Data on women with and without breast cancer are presented separately because they are distinct groups. Our goal was not to compare the two cohorts but to learn about the experiences of these women to inform screening, diagnostics, and treatment of breast cancers. We present a subset of the data elements and measures collected to explore the barriers to seeking care and women’s treatment experiences.

We present descriptive statistics on demographics, socioeconomic factors, stage at diagnosis (breast cancer survivors only; based on the American Joint Commission on Cancer staging system), family history of breast cancer, employment status, insurance coverage, and approaches used to identify funds to pay for medical expenses. For women without a breast cancer diagnosis, we present barriers to seeking help by analyzing responses to this specific domain from the Breast Cancer Awareness Measure (BCAM). The proportions we present are based on the number of participants who responded "Yes, often" or "Yes, sometimes." The other response options were "No," "Don't know," and "Refused." For women with breast cancer, we report details on their medical and nonmedical expenses, whether their insurance coverage met their expectations for reimbursement, whether they had foregone care for financial reasons, and whether the cost of treatment was discussed with the doctor. Last, we summarize qualitative feedback received from both women with and without breast cancer on their concerns and ideas to improve breast cancer care in Kenya.

**3. Results**

We recruited 400 participants with breast cancer and 400 participants without breast cancer for this study over a 6-month period. Table 2 summarizes the demographic and clinical variables of the 800 subjects, stratified by survey cohort. The average age of a participant with breast cancer in our study was 46.1 years, Most women in the sample lived in “the countryside,” and the next most common regions where the women lived included major cities like Nairobi and Mombasa. The most frequent level of educational attainment was secondary/vocational school (37.3 %); women without breast cancer 38.5 %), followed by primary school (34.0 %). Most of the participants were married (61.0 %; In terms of clinical factors, the most frequently reported breast cancer stages at diagnosis were stage II (39.5 %) and stage III (30.3 %); 11.7 % of the women did not know their stage. Overall, 17.5 % of women with breast cancer had one or more first-degree

**Table 2**  
Demographic Characteristics by Survey Cohort.

	Women Breast Cancer			
	With (n = 400)		Without (n = 400)	
	n	%	n	%
Age				
Mean age	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
<b>Place of residence</b>				
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
<b>Educational attainment</b>				
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
<b>Marital status</b>				
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
<b>Breast cancer stage at diagnosis</b>				
Stage 0	10	2.5	–	–
Stage I	31	7.8	–	–
Stage II	158	39.5	–	–
Stage III	121	30.3	–	–
Stage IV	30	7.5	–	–
Don't know	47	11.8	–	–
Missing	3	0.8	–	–
<b>Do you have a close relative who has been diagnosed with breast cancer?</b>				
Yes	70	17.5	45	11.3
No	327	81.8	351	87.8
Missing	3	0.8	4	1.0

(parents, full siblings, or children) relatives with a breast cancer diagnosis. The average for a participant without breast cancer was 39.2 years and the majority lived in the countryside. More than a third of these women had attended secondary/vocational school (38.5 %) while about a quarter had a college education (27.3 %). Among these women,

**Table 3**  
Employment and Insurance-Related Variables by Survey Cohort.

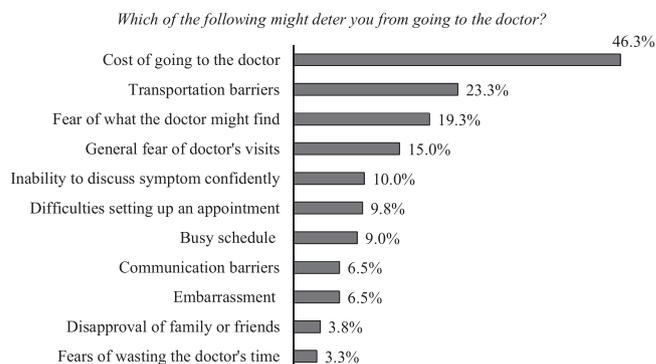
	Women Breast Cancer			
	With (n = 400)		Without (n = 400)	
	n	%	n	%
Are you employed or working for pay?				
Yes	132	33.0	258	64.5
Not now, but I plan to seek future	134	33.5	86	21.5
Not now, nor in the foreseeable future	127	31.8	49	12.3
Missing	7	1.8	7	1.8
<b>At the time you were diagnosed with breast cancer, were you employed or working for pay?</b>				
Yes	247	61.8	–	–
No	148	37.0	–	–
Missing	5	1.3	–	–
<b>How many days of work did you miss due to your breast cancer diagnosis?</b>				
Among women who were working at the time of diagnosis*				
0 days	4	1.6	–	–
1 – 21 days	12	4.9	–	–
22 – 29 days	128	51.8	–	–
> 30 days	95	38.5	–	–
Missing	8	3.2	–	–
<b>What type of medical insurance do you have?</b> (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
<b>How do you pay for medical services and other related expenses?</b>				
I use my income and/ or savings	280	70.0	296	74.0
I use funds from my Health Saving Account	96	24.0	57	14.3
I borrow money from family/ friends	312	78.0	83	20.8
I receive support from charities/ fundraising	138	34.5	7	1.8
I borrow against my home or other assets	16	4.0	6	1.5
I leave some of my medical bills unpaid	17	4.3	6	1.5
I increase my credit card debt	17	4.3	3	0.8
I postpone paying personal bills	57	14.3	11	2.8
I sell personal belongings	137	34.3	9	2.3
I use another method (bank loans, etc.)	20	5.0	8	2.0

\* During the first 12-month period after diagnosis.

56.5 % were married and 11.3 % had some family history of breast cancer.

In Table 3, we report on variables pertaining to the employment and insurance status of each cohort. At the survey date, women without breast cancer were twice as likely to be employed (64.5 %) than women with breast cancer (33.0 %), although roughly one-third of these survivors planned to look for employment in the future. Furthermore, at the date of diagnosis, the percentage (61.8 %) of breast cancer survivors who were employed was almost equal to the rate for women without breast cancer, suggesting that the variation between the two groups largely appeared post-diagnosis. Among women who were working at the time of their diagnosis, the most frequently cited number of days missed due to breast cancer treatment was between 22–29 days (51.8 %), followed by more than 30 days (38.5 %). Almost 70 % of the women with breast cancer had insurance compared to about half of the women without breast cancer. To cover out-of-pocket medical costs and related expenses, women with breast cancer most frequent (78.0 %) reported borrowing money from family or friends, while most (74.0 %) women without breast cancer relied on their personal income and savings for these types of expenditures.

Fig. 1 displays the results from the BCAM as they pertain to barriers to seeking medical care, including screening and diagnostic tests



**Fig. 1.** Breast Module of the Cancer Awareness Measure (Breast-CAM) Responses Among the Comparison Group.

required for early stage cancer diagnosis, by women without breast cancer. The most commonly cited impediment to receiving medical care was cost (46.3 %), followed by transportation (23.3 %) and fear of what the doctor might find (19.3 %). Conversely, the least often reported items were embarrassment (6.5 %), disapproval of family or friends (3.8 %), and fear of wasting the doctor's time (3.3 %).

Table 4 reports on medical costs, nonmedical costs, and care experiences of women with breast cancer. The most commonly reported treatment expenditure was between 200,001–500,000 Kenyan shillings (KES)—an amount equal to roughly 2001–5000 United States dollars (USD). Some women (16.5 %), however, reported spending more than 1 million KES (10,000 USD). Only about a third (36.6 %) of the survivors indicated that their health insurance covered more or about what they expected of their medical bills. In addition to these medical costs, over half of the women (67.3 %) in this cohort spent more than 50,000 KES (500 USD) on nonmedical expenses. Most women (91.5 %) reported that the breast cancer diagnosis impacted their finances “very much” or “quite a bit.” The substantial financial outlays reported by the women with breast cancer often caused them to delay or stop treatment (37.0 %), go without prescribed medication (31.8 %), and miss doctor's appointments (29.3 %), among other effects. Overall, 53.8 % of the women reported that they had to forego care because of the cost. However, the vast majority (77.8 %) did not consider cost when choosing a treatment course, and roughly two-thirds did not discuss the cost of treatment with their doctor.

In Table 5, we report qualitative responses received from the participants on concerns and approaches to improve breast cancer screening, diagnosis, treatment, and follow-up care. We received feedback from 22.5 % of the women without breast cancer and 33.7 % of the women with breast cancer. Among women without breast cancer, education and awareness was cited most frequently (50.0 %); for example, one woman responded that “breast self-exam education is not adequate.” Topics surrounding access (27.3 %) and cost (20.0 %) were also frequently cited by women without breast cancer and were reflected in comments such as “Free screening should be available.” For women with breast cancer, the most common response pertained to availability and access issues (40.0 %), followed by cost and financing aspects (34.5 %). The problem of availability and access elicited comments such as “Drug availability is a problem” and “Long queues delay treatment.” Feedback related to cost included comments such as “Cost of treatment is too high, especially Herceptin.” Another woman with breast cancer lamented that there was “extensive out of pocket financing... for tests not covered by NHIF.”

#### 4. Discussion

In this study, we interviewed women with and without a diagnosis of breast cancer in Kenya to evaluate barriers, with a specific focus on the financial impediments to breast cancer screening and treatment. For

**Table 4**  
Insurance and Medical Cost Measures in Women with Breast Cancer.

	Women with Breast Cancer (n = 400)	
	n	%
What were your total medical expenses related to breast cancer treatment? <sup>a</sup>		
Less than Ksh 50,000	10	2.5
Ksh 50,001–Ksh 200,000	73	18.3
Ksh 200,001–Ksh 500,000	134	33.5
Ksh 500,001–Ksh1,000,000	93	23.3
More than Ksh1,000,000	66	16.5
Don't know	19	4.8
Missing	4	1.0
How did your insurance coverage compare with your expectations?		
I did not have insurance	119	29.8
It covered more than I expected	81	20.3
It covered about what I expected	65	16.3
It covered less money than I expected	118	29.5
Missing	17	4.3
How much have you paid for non-medical expenses related to your care? <sup>a</sup>		
Less than Ksh 50,000	116	29.0
Ksh 50,001–Ksh 200,000	215	53.8
Ksh 200,001–Ksh 500,000	44	11.0
Ksh 500,001–Ksh1,000,000	4	1.0
More than Ksh1,000,000	6	1.5
Missing	15	3.8
Did you experience financial impacts due to your breast cancer and treatment?		
Not much at all	7	1.8
A little	11	2.8
Somewhat	12	3.0
Quite a bit	26	6.5
Very much	340	85.0
Missing	4	1.0
Because of your medical cost over the past year, did you have to...		
Delay or stop treatment?	148	37.0
Go without any medication prescribed?	127	31.8
Take less than the full amount of a prescription?	100	25.0
Miss a doctor's appointment?	117	29.3
Miss any recommended follow up tests?	115	28.8
Delay or forgo breast reconstruction?	66	16.5
Forgo fertility preservation?	16	4.0
Experienced any of the above	215	53.8
What was the effect of cost on your treatment decisions?		
I did not discuss the cost of treatment with the doctor	268	67.0
I did not consider cost when choosing a treatment course	311	77.8

<sup>a</sup> Note: As of September 25, 2018, approximately 100 Kenyan Shillings (KES) equals one United States Dollar (USD).

both women without and women with breast cancer, cost was a major concern in seeking medical services. Women without cancer indicated that the cost of medical services and transportation were key barriers they faced when seeking required care. These barriers can result in late stage diagnosis of breast cancer. In their qualitative feedback, women advocated for free or low-cost testing to increase breast cancer screening in Kenya. It is also important to note that nonmedical costs, including expenses related to travel, meals, and housing, can be major barriers to seeking medical care. Efforts should be made to offer screening and diagnostic services in dispersed geographic locations to improve access and reduce nonmedical costs borne by the patient. At the time of their diagnosis, most Kenyan women with breast cancer are in the later stages of the disease and improving the availability of screening services is crucial to increase early stage diagnosis and reduce the financial outlays required for breast cancer treatment. Research by our team and others has shown that high breast cancer treatment costs can lead to catastrophic health expenditures and household impoverishment. [18,25,26] Additionally, as highlighted in the feedback provided by the participants, education and awareness of approaches to improve knowledge of breast cancer symptoms and screening options are also required. With enhanced knowledge, Kenyan women will be better able to identify physical breast changes that might be indicative of breast cancer and to choose to undergo regular screening.

For women with breast cancer, 53.8 % reported that they had to forego care because of cost. About a third had to delay or stop treatment and could not afford their prescribed medications. Others reported that they missed appointments or follow-up tests. Therefore, the cost of breast cancer treatment in Kenya results in significant access barriers that will impact patients' quality of care and increase morbidity and mortality from this disease. [27] Additionally, 91.2 % of the women reported that their diagnosis impacted household financial wellbeing. Two-thirds of the women with breast cancer had health insurance but about half of them reported that the insurance did not cover as much of their medical cost as they expected. The NHIF is a major source of medical insurance for Kenyans and, although breast cancer treatment modalities (i.e., surgery, chemotherapy, and radiation) are reimbursed, diagnostic procedures and tests may not be covered [18].

Another key finding from this study is that patients do not actively consider cost in developing their breast cancer treatment plans. Women should be provided with tools to empower them to engage in meaningful discussions about the cost of their treatment with their physicians and insurance providers. This will enable women to prioritize care pathways to maximize the benefits received and provide opportunities to plan to secure the funding they need. Furthermore, it is essential that women with a breast cancer diagnosis receive counseling about their future financial wellbeing, because many women are unable to continue

**Table 5**  
Qualitative Feedback Response on Approaches to Improve Cancer Screening and Treatment.

	Women Without Breast Cancer – Recommendations to improve access to screening (n = 400)			Women With Breast Cancer – Recommendations to improve access to treatment (n = 400)		
	n	%	Example Responses	n	%	Example Responses
<b>Gave feedback</b>	102	25.5		135	33.7	
<b>Response categories</b>						
Improved availability of services	30	27.3	"Breast cancer screening should be at local health centers"	58	40.0	"Drug availability is a problem"
Financial assistance to address high cost	22	20.0	"Free screening should be available"	50	34.5	"The cost for cancer treatment is too high"
Better education and support groups	55	50.0	"Breast self-exam education is not adequate"	12	8.3	"No support groups where I stay"
Disinformation about cancer should be mitigated	3	2.7	"Women at village levels believe cancer is witchcraft"	10	6.9	"Cancer treatment drugs have serious side effects"
No specific concerns	–	–		15	10.3	"The treatment process is okay"

Note: The number of response categories exceeds the number of subjects who gave qualitative feedback because some responses touched on more than one category, and were coded accordingly.

working during their treatment or to return to work soon after completing treatment. Finally, the cost of breast cancer treatment can differ based on whether care was provided in the public or private sector hospitals, and there could be variation in the types of services covered by health insurance. These aspects could impact the out-of-pocket costs reported by the women in our study.

A key strength of this study is that the study sample included prospective data from 800 women from both cities and rural areas. However, the analysis is based on responses provided by the women themselves, which may be subject to recall or other biases. Women were interviewed by research assistants, which could have also introduced bias. We attempted to minimize this by providing comprehensive training to the research assistants in breast cancer disease processes, optimal interview techniques, approaches to ensure that respondents' views were respected, and resources to offer respondents who may have experienced any distress in answering the questions posed to them. Moreover, 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 might not be generalizable to the entire country. We also recruited women consecutively and included those who volunteered to participate; this non-random selection process could have introduced selection bias. Additionally, since we only had a small sample of women with private insurance, we were unable to conduct stratified analysis to evaluate potential differences by type of insurance coverage.

Despite these few limitations, the findings from this study provide important insight into financial barriers experienced by women in Kenya when seeking breast cancer screening and treatment. A multifaceted approach is required to improve breast cancer education and increase access to screening and treatment services by ensuring affordability and availability. Ensuring greater insurance coverage for screening and diagnosis of breast cancer, which are generally not covered by health insurance in Kenya, is essential to reduce late-stage diagnosis of breast cancers.

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#### Declaration of Competing Interest

The authors declare that there is no conflict of interest.

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Kenya Cancer Association (KENCANSA), their membership, and affiliated support groups.

#### References

- [1] Ministry of Health. National Cancer Control Strategy, (2017)–2022 [Internet] <http://kehpc.org/wp-content/uploads/KENYA-NATIONAL-CANCER-CONTROL-STRATEGY-2017-2022.pdf>.
- [2] A. Korir, N. Okerosi, V. Ronoh, G. Mutuma, M. Parkin, Incidence of cancer in Nairobi, Kenya (2004–2008), *Int. J. Cancer* 137 (9) (2015) 2053–2059, <https://doi.org/10.1002/ijc.29674>.
- [3] International Agency for Research on Cancer. GLOBOCAN—Global Cancer Observatory [Internet]. Lyon, France, (2019) <http://gco.iarc.fr/>.
- [4] National Institute of Health, National Cancer Institute, Surveillance, Epidemiology and End Results Programme, (2018) <https://seer.cancer.gov/statfacts/html/breast.html>.
- [5] J. Kisiangani, J. Baliddawa, P. Marinda, H. Mabeya, J.K. Choge, E.O. Adino, C. Khayeka-Wandabwa, 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 (1) (2018) 81, <https://doi.org/10.1186/s12905-018-0571-7>.
- [6] M. Ly, M. Antoine, F. André, P. Callard, J.-F. Bernaudin, D.A. Diallo, Breast cancer in sub-Saharan African women: review, *Bull. Cancer* 98 (7) (2011) 797–806, <https://doi.org/10.1684/bdc.2011.1392>.
- [7] R. Luengo-Fernandez, J. Leal, A. Gray, R. Sullivan, Economic burden of cancer across the European Union: a population-based cost analysis, *Lancet Oncol.* 14 (12) (2013) 1165–1174, [https://doi.org/10.1016/S1470-2045\(13\)70442-X](https://doi.org/10.1016/S1470-2045(13)70442-X) Epub 2013 Oct 14.
- [8] K. Meneses, A. Azuero, L. Hassey, P. McNees, M. Pisu, Does economic burden influence quality of life in breast cancer survivors? *Gynecol. Oncol.* 124 (3) (2012) 437–443, <https://doi.org/10.1016/j.ygyno.2011.11.038> Epub 2011 Nov 29.
- [9] Y.A. Kim, I.H. Oh, S.J. Yoon, H.J. Kim, H.Y. Seo, E.J. Kim, Y.H. Lee, J.H. Jung, The economic burden of breast cancer in Korea from 2007–2010, *Cancer Res. Treat.* 47 (4) (2015) 583–590, <https://doi.org/10.4143/crt.2014.143> Epub 2015 Feb 13.
- [10] R. Jaggi, J.A.E. Pottow, K.A. Griffith, C. Bradley, A.S. Hamilton, J. Graff, S.J. Katz, S.T. Hawley, Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries, *J. Clin. Oncol.* 32 (12) (2014) 1269–1276.
- [11] C.K. Altice, M.P. Banegas, R.D. Tucker-Seeley, K.R. Yabroff, Financial hardships experienced by cancer survivors: a systematic review, *J. Natl. Cancer Inst.* 109 (2) (2017), <https://doi.org/10.1093/jnci/djw205>.
- [12] N. Saito, M. Takahashi, T. Sairenchi, T. Muto, The impact of breast cancer on employment among Japanese women, *J. Occup. Health* 56 (1) (2014) 49–55.
- [13] K.R. Yabroff, E.C. Dowling, G.P. Guy Jr, M.P. Banegas, A. Davidoff, X. Han, K.S. Virgo, T.S. McNeel, N. Chawla, D. Blanch-Hartigan, E.E. Kent, C. Li, J.L. Rodriguez, J.S. de Moor, Z. Zheng, A. Jemal, D.U. Ekwueme, Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors, *J. Clin. Oncol.* 34 (3) (2016) 259–267.
- [14] G.P. Guy Jr, D.U. Ekwueme, K.R. Yabroff, E.C. Dowling, C. Li, J.L. Rodriguez, J.S. de Moor, K.S. Virgo, Economic burden of cancer survivorship among adults in the United States, *J. Clin. Oncol.* 31 (30) (2013) 3749–3757.
- [15] E.A. Finkelstein, F.K. Tangka, J.G. Trogdon, S.A. Sabatino, L.C. Richardson, The personal financial burden of cancer for the working-aged population, *Am. J. Manag. Care* 15 (11) (2009) 801–806.
- [16] J.R. Moran, P.F. Short, C.S. Hollenbeck, Longterm employment effects of surviving cancer, *J. Health Econ.* 30 (2011) 505–514.
- [17] S. Flessa, M. Moeller, T. Ensor, K. Hornetz, Basing care reforms on evidence: the Kenya health sector costing model, *BMC Health Serv. Res.* 11 (2011) 128, <https://doi.org/10.1186/1472-6963-11-128>.
- [18] S. Subramanian, R. Gakunga, J. Kibachio, G. Gathecha, P. Edwards, E. Ogola, G. Yonga, N. Busakhala, E. Munyoro, J. Chakaya, N. Ngugi, N. Mwangi, D. Von Rege, L.M. Wangari, D. Wata, R. Makori, J. Mwangi, W. Mwanda, Cost and affordability of non-communicable disease screening, diagnosis and treatment in Kenya: patient payments in the private and public sectors. *East African Economics and Implementation Group (EAEIG)*, *PLoS One* 13 (1) (2018) e0190113, <https://doi.org/10.1371/journal.pone.0190113> eCollection 2018.
- [19] Exploring Kenya's Inequality; Pulling Apart or Pooling Together; (2013) Available at [http://www.knbs.or.ke/index.php?option=com\\_content&view=article&id=279:exploring-%09kenya-s-inequality-pulling-apart-or-pooling-together&catid=82&Itemid=593](http://www.knbs.or.ke/index.php?option=com_content&view=article&id=279:exploring-%09kenya-s-inequality-pulling-apart-or-pooling-together&catid=82&Itemid=593).
- [20] P. Baili, F. Di Salvo, F. de Lorenzo, F. Maietta, C. Pinto, V. Rizzotto, M. Vicentini, P.G. Rossi, R. Tumino, P.C. Rollo, G. Tagliabue, P. Contiero, P. Candela, T. Scuderi, E. Iannelli, S. Cascinu, F. Aurora, R. Agresti, A. Turco, M. Sant, E. Meneghini, A. Micheli, *Support. Care Cancer* 24 (5) (2016) 2225–2233, <https://doi.org/10.1007/s00520-015-3019-8> Epub 2015 Nov 16.
- [21] Kenya national bureau of statistics, Kenya Demographic and Health Survey 2015 (2014) 440–441.
- [22] Breast Cancer Risk Assessment Tool Cancer.gov, (2017) Available at: <https://www.cancer.gov/bcrisktool/>.
- [23] L. Linsell, L.J. Forbes, C. Burgess, et al., Validation of a measurement tool to assess awareness of breast cancer, *Eur. J. Cancer* 46 (8) (2010) 1374–1381.
- [24] Questionnaires Facit.org, (2017) [cited 19 July 2017]. Available from: <http://www.facit.org/facitorg/questionnaires>.
- [25] E.W. Barasa, T. Maina, N. Ravishanker, Assessing the impoverishing effects, and factors associated with the incidence of catastrophic health care payments in Kenya, *Int. J. Equity Health* 16 (1) (2017) 31, <https://doi.org/10.1186/s12939-017-0526-x>.
- [26] L. Jaspers, V. Colpani, L. Chaker, S.J. van der Lee, T. Muka, D. Imo, S. Mendis, R. Chowdhury, W.M. Bramer, A. Falla, R. Pazoki, O.H. Franco, The global impact of non-communicable diseases on households and impoverishment: a systematic review, *Eur. J. Epidemiol.* 30 (3) (2015) 163–188, <https://doi.org/10.1007/s10654-014-9983-3> P.
- [27] E.E. Kent, L.P. Forsythe, K.R. Yabroff, K.E. Weaver, J.S. de Moor, J.L. Rodriguez, J.H. Rowland, Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer* 119 (20) (2013) 3710–3717, <https://doi.org/10.1002/cncr.28262>.