

# Self-perceived Risk of Breast Cancer and Screening Behaviors of First-degree Female Relatives of Breast Cancer Patients at the Uganda Cancer Institute, Uganda

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## Research Article

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# Abstract

## Introduction

In Uganda, Breast cancer is the most common cancer in females globally. The majority of the patients present with advanced-stage disease at diagnoses and experience high mortality. This underscores the importance of early detection approaches based on awareness of risk factors and self-perceived risks, and symptoms of the disease to promote adoption of risk reduction behaviors and prompt health-seeking respectively. This study assessed the self-perceived risk of breast cancer, and breast cancer screening behaviours among first-degree female relatives of breast cancer patients in Uganda.

## Methods

This was a cross-sectional study employing quantitative approaches for data collection and analyses. First-degree female relatives of patients attending care at Uganda Cancer Institute were recruited consecutively in the study. A pre-tested coded questionnaire was used to collect data on self-perceived risks, breast cancer risks, and breast cancer screening behaviours. Data were collected between March to October 2019. A modified Poisson regression model was used to evaluate factors associated with self-perceived risk of breast cancer and breast cancer risk awareness.

## Results

We enrolled 296 first-degree female relatives from 197 female breast cancer patients. The median age (IQR) was 33 (26-43) years. A majority (60.1%, 178/296) of the participants had a low self-perceived risk of breast cancer. Breast self-examination (55.7%, 165/296) was the most practiced screening method followed by clinical breast examination (n= 64/296, 21.6%), ultrasound scan of the breast (7.8%, 23/296), and mammogram (3.7%, 11/296). Women aged 35-44 years had a higher self-perceived risk of breast cancer (adjusted Incident Rate Ratio [aIRR]: 1.75, 95%CI: 1.10-2.80), compared to women aged 18-25 years.

## Conclusion

First-degree relatives reported a low self-perceived risk of breast cancer. Breast cancer health education especially targeting younger women should emphasize the increased risk of breast cancer in first-degree relatives of patients with breast cancer. There is a need to increase awareness of breast cancer screening methods and their usefulness in the early detection of breast cancer among all women in Uganda.

## Introduction

Breast cancer is the most common malignancy among women in developing and developed countries(1). In 2018 and 2020, it was estimated that 2.1 million and 2.3 million new breast cancer cases were diagnosed constituting 11.6% and 11.7% of all incident cancer cases worldwide respectively (1–3). In Uganda, 2,639 new cases of breast cancer were recorded in 2020, accounting for 7.8% of all new cancer

cases in both sexes. Among females, breast cancer incidence (13.5% of all female cancers) was only second to cervical cancer and accounted for 5.9% of all deaths from cancers(1). While there is a high incidence of breast cancer in high-income countries, the disease causes more mortality in Low- and Middle-Income Countries (4–6). The predominantly advanced-stage cancer at diagnoses and high mortality rate in the less developed countries has been attributed to the lack of adequate facilities for diagnosis and treatment and early detection programs (7–9). This is in contrast to developed countries where survival rates are high and screening programs available particularly for populations that are at higher risk of breast cancer (10). Screening for breast cancer has been associated with a reduction in mortality from the disease (11). This underscores the importance of ensuring the availability of screening services particularly for populations that are at high risk. Uptake of screening services and adoption of risk reduction strategies, in general, depends on several factors including awareness, availability of the services, and self-perceived risk to the disease/cancer.

First-degree relatives (FDRs) of breast cancer patients experience an elevated risk of breast cancer compared to the general population (12). Females who are related to at least one breast cancer patient are more than two times likely to develop breast cancer compared to those without a family history of breast cancer. The risks of developing breast cancer are even higher when they are related to more than one patient (13–15). Because FDRs are at increased susceptibility to breast cancer, several studies have explored how FDRs understand their risk of breast cancer and how this informs their adoption of risk reduction and health-seeking behaviors (16–18). Understanding the self-perceived risks and awareness of breast cancer risk factors and symptoms of FDRs of breast cancer patients potentially guides policymakers and healthcare professionals on the design of targeted interventions to promote risk reduction and prompt health-seeking for symptoms of breast cancer among the FDRs of breast cancer patients. However, there are limited data on self-perceived risk for breast cancer and screening behaviors of the FDRs of breast cancer patients in Uganda. Therefore, the purpose of this study was to assess the self-perceived and screening behaviors of FDRs of breast cancer patients attending care at the Cancer Institute in Uganda to inform interventions to promote risk factor awareness, an appropriate understanding of self-risks, adoption of risk reduction behaviors, and prompt health-seeking for symptoms suggestive of breast cancer.

## **Methods**

### **Study design and site**

This was a cross-sectional study conducted at the breast cancer clinic and in-patient wards of the Uganda Cancer Institute (UCI). The Uganda Cancer Institute is a tertiary cancer care facility located in Kampala, Uganda. The Institute is the main specialized cancer center for training, research, and patient care in the country(19).

### **Study Population**

We enrolled female FDRs of female breast cancer patients (daughter, sister, or mother to a female breast cancer patient) receiving care at the UCI. Participants were included in the study if they were aged 18 years and older, had no personal history of breast cancer, willing to provide written informed consent to participate in the study, and able to express themselves in English or Luganda (the predominant language in Kampala).

## **Participant recruitment and data collection**

Consecutive sampling was used to enroll female first-degree relatives of breast cancer patients. The breast cancer patients were approached as they waited for treatment from the out-patients clinic. Also, stable patients who were admitted in the wards were approached and requested to identify FDRs who could be included in the study. If the patient had three or fewer first-degree female relatives, all of them were included in the study. In cases where the patient had more than three first-degree female relatives, the first three who were able to travel to the UCI for the interview were considered. The FDRs were individually contacted and requested to travel to the UCI for an interview. Those who managed to travel were given information about the objectives of the study and provided with the opportunity to ask questions. Informed consent was then sought from those who agreed to participate in the study. Interviews were conducted in a quiet room with sufficient privacy. Trained research assistants collected data under the supervision of the investigators. The research assistants followed written Standard Operating Procedures (SOPs) for recruitment, consenting, and data collection. Each interview lasted about 30 minutes. All study procedures were performed in accordance with Good Clinical Practice, National and International guidelines and regulations for the conduct of research.

## **Measurements**

Data were collected using an interviewer-administered questionnaire either in English or Luganda. The first part of the questionnaire assessed participants' socio-demographic characteristics e.g. age, marital status, education attainment, religion, and region of residence in Uganda. The second part assessed breast cancer self-perceived risk using a verbal measure that has been used in previous studies (20). The verbal measure explores participant's response to the question; 'My chances of getting breast cancer are great' on a Likert scale with 5 response alternatives (strongly disagree (1), disagree (2), neutral (3), agree (4), and strongly agree (5)). At analysis, a participant was categorized to have low self-perceived risk if she selected strongly disagree or disagree, and high self-perceived risk if she selected neutral, agree, or strongly agree as a response to the above question. The third part assessed breast cancer risk reduction behaviours i.e. self-breast examination, clinical breast examination, ultrasound scan, and mammography. The questionnaire was pre-tested with the relatives of breast cancer patients at Uganda Cancer Institute. The women included in the pre-test did not participate in the main study.

## **Data management and analysis**

Data was done using Epidata version 3.1 software. The final data was backed up before exporting a copy to STATA version 14.1 for analysis. We described the study population using proportions for categorical variables; medians and interquartile range for continuous variables. At bivariable analysis, we examined the associations between socio-demographic characteristics, breast cancer screening, and breast cancer self-perceived risk using chi-square tests and rank-sum tests respectively. We used a modified Poisson regression model to evaluate factors associated with the self-perceived risk of breast cancer among the participants (21, 22). Poisson regression models with robust variances were used to estimate incidence rate ratios at 95% confidence intervals. Rate ratios closely approximate risk ratios when the outcome is common (21, 23).

## Results

### **Social demographic characteristics of first-degree female relatives**

We enrolled 296 first-degree relatives of 197 female breast cancer patients. The median age (IQR) of the participants was 33 (26–43) years. Most of the participants were aged between 26–35 years (36.1%, 107/296). The majority of the participants were married (50.3%, 149/296), attained at least secondary education (33.1%, 98/296), and were from the central region (58.8%, 174/296) (Table 1).

Table 1  
Social demographic characteristics of first-degree female relatives

<b>Socio-demographic factors</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Age; median (IQR)</b>	33 (26–43)	
18–25	68	23.0
26–35	107	36.1
36–45	63	21.3
≥ 46	58	19.6
<b>Marital status</b>		
Married	149	50.3
Single	113	38.2
Divorced	21	7.1
Widow	13	4.4
<b>Religion</b>		
Catholic	104	35.1
Anglican	77	26.0
Moslem	58	19.6
Born again	47	15.9
Other	10	3.4
<b>Education level</b>		
None	9	3.0
Primary	71	24.0
Secondary	98	33.1
Tertiary	58	19.7
University	59	19.9
Missing	01	0.3
<b>Residence</b>		
Rural	112	37.8
Urban	183	61.8

Socio-demographic factors	Frequency	Percentage
Missing	01	0.4
<b>Origin</b>		
Central	174	58.8
Western	33	11.2
Eastern	55	18.5)
Northern	34	11.5

## Self-perceived of breast cancer and associated factors

A majority (60.1%, 178/296) of the participants perceived themselves to be at low risk of developing breast cancer. Age was the only factor significantly associated with a high self-perceived risk of developing breast cancer among the first-degree female relatives of the breast cancer patients. After controlling for education level, area of residence, and religion, women aged 35–44 years had a higher self-perceived risk of breast cancer (adjusted Incident Rate Ratio [aIRR]: 1.75, 95% CI: 1.10–2.80) compared to women aged 18–25 years (Table 2).

Table 2  
Socio-demographic factors and self-perceived risk of breast cancer

Characteristics	Unadjusted Incident Risk ratios (95% CI)	P-value	Adjusted Incident Risk Ratio (95% CI)	P-value
<b>Socio-demographic factors</b>				
<b>Age group</b>				
18–25	1.00		1.00	
26–35	1.47 (0.94–2.30)	0.09	1.50 (0.96–2.36)	0.08
36–45	1.76 (1.11–2.78)	<b>0.02</b>	1.75 (1.10–2.80)	<b>0.02</b>
>=46	1.48 (0.91–2.42)	0.12	1.45 (0.88–2.40)	0.15
<b>Marital status</b>				
Married	1.00			
Single	1.01 (0.77–1.34)	0.93		
<b>Religion</b>				
Christian	1.00		1.00	
Moslem	1.34 (0.98–1.82)	0.06	1.30 (0.96–1.77)	0.09
<b>Education level</b>				
Primary	1.00			
Secondary	0.93 (0.66–1.30)	0.67		
Tertiary/ University	0.78 (0.55–1.10)	0.16		
<b>Residence</b>				
Urban	1			
Rural	1.22 (0.92–1.62)	0.93		
<b>Region</b>				
Central	1			
Western	0.90 (0.56–1.47)	0.68		
Eastern	0.99 (0.69–1.44)	0.98		
Northern	1.02 (0.66–1.59)	0.92		

## Breast cancer screening practices

One hundred and sixty-five (55.7%, 165/296) participants self-reporting ever performing Breast Self-Examination (BSE); 66% (109/165) of them had last examined their breasts within a month of this study interview. The median age (Interquartile range, IQR) at which first-degree relatives began performing BSE was 28 (22–37) years. Only 21.6% (64/296) of the first-degree relatives had ever visited a healthcare professional for a Clinical Breast Examination (CBE). Of those who underwent CBE, 42.2% (27/ 64) visited a healthcare professional for CBE because they wanted to know their breast cancer status. Only 7.8% (23/296) of all first-degree relatives had ever had an ultrasound scan of the breast. The most cited reason for performing an ultrasound scan of the breast was self-noticed changes in the breast (60.9%, 14/23) (Table 3).

Table 3  
Breast cancer screening practices

<b>Self-breast examination</b>	<b>Frequency</b>	<b>percentages</b>
<b>Performs breast self-examination</b>		
Yes	165	55.7
No	131	44.3
<b>Perform breast self-examination every (N = 165)</b>		
Every 6 months	21	12.7
Once a month	73	44.3
Once a week	33	20.0
Others	38	23.0
<b>Last performed the breast self-examination (N = 165)</b>		
Less than a month ago	109	66.1
2–6 months ago	29	17.6
6 months – 1 year ago	21	12.7
More than 1 year ago	3	1.8
Missing	3	1.8
<b>Age of first breast self- examination; median (IQR), (N = 165)</b>		28 (22–37)
<b>Clinical breast examination:</b>		
<b>Ever visited a doctor for a clinical breast examination</b>		
Yes	64	21.6
No	232	78.4
<b>Last visited a doctor for a clinical breast exam (N = 64)</b>		
Less than a month ago	9	14.1
2–6 months ago	15	23.4
6 – 1 year ago	13	20.3
More than 1 year ago	27	42.2
<b>Indication for Clinical Breast Examination (N = 64)</b>		
Noticed a change in my breast	18	28.1
Wanted to know their breast cancer status	27	42.2

<b>Self-breast examination</b>	<b>Frequency</b>	<b>percentages</b>
Medical advice/procedure	18	28.1
Missing	1	1.6
<b>Ultrasound scan</b>		
<b>Ever done an ultrasound scan of the breast</b>		
Yes	23	7.8
No	273	92.2
<b>Last performed an ultrasound scan of the breast (N = 23)</b>		
Less than a month ago	1	4.4
2–6 months ago	3	13.0
6months – 1 years ago	7	30.4
More than 1 year ago	12	52.2
<b>Indication for the ultrasound scan of the breast (N = 23)</b>		
Noticed a change in the breast	14	60.9
Wanted to know their breast cancer status	6	26.1
Medical advice/procedure	3	13.0
<b>Mammography</b>		
<b>Ever done mammography</b>		
Yes	11	3.7
No	285	96.3
<b>Mammography last done (N = 11)</b>		
2–6 months ago	2	18.2
6 months – 1 year ago	3	27.3
More than 1 year ago	6	54.5
<b>Indication for Mammography</b>		
Noticed a change in the breast	5	45.5
Wanted to know their breast cancer status	4	36.4
Medical advice/Procedure	2	18.2

# Breast cancer self-perceived risk and breast cancer screening behaviors

We did not find significant associations between age, marital status, education, and other socio-demographic factors of the participants with the self-perceived risk of breast cancer (Table 4).

Table 4  
Associations between self-perceived risk and risk reduction behaviors

Variable	Low Risk n (%)	High risk n (%)	P-Value
<b>Breast Self-Examination</b>			0.31
Yes	95 (53.4)	70 (59.3)	
No	83 (46.6)	48 (40.7)	
<b>Clinical Breast Examination</b>			0.66
Yes	40 (22.5)	24 (20.3)	
No	138 (77.5)	94 (79.7)	
<b>Ultrasound Scan of the breast</b>			0.60
Yes	15 (8.4)	8 (6.8)	
No	163 (91.6)	110 (93.2)	
<b>Mammography</b>			1.00 <sup>1</sup>
Yes	7 (3.9)	4 (3.4)	
No	171 (96.1)	114 (96.6)	

## Discussion

We found that less than half of the participants perceived themselves to be at a high risk of developing breast cancer especially because they had a relative with breast cancer. Older women were more likely to perceive themselves to be at higher risk of developing breast cancer, mainly because they had a relative with breast cancer. We found a low uptake of breast cancer screening services among this study population. Mammography was the least undertaken of the risk reduction and screening behaviors (others self-breast examinations, clinical breast examinations and breast ultra sound scans) assessed in this study.

Risk perception is critical in determining an individual's appraisal of susceptibility to disease and influences the likelihood of taking a preventive action (24). In this study, less than half of the participants

perceived themselves to be at risk of breast cancer. This finding is lower than the fifty-five percent reported by Royak-Schaller et al (1995) but close to results from a recent quantitative study by Seven et al (2018) where almost half of the participants moderately worried about the chance of getting breast cancer and another fifty percent ranked their risk as moderate (18, 25). In a qualitative study by Spector et al (2009), women perceived themselves to be at a heightened risk of breast cancer and nearly one-fifth of the respondents considered themselves below average risk (26). Understanding cancer self-perceived risk can be challenging and it is not unusual to find discrepancies between perceived and objective breast cancer risk. This may arise from the way participants understand the concept of risk (27). It may also be due to misleading information from the media and inadequately informed healthcare professionals.

We also found that breast cancer self-perceived risk was significantly associated with the age of the participant. The strength of the association between age and risk perception increased for participants aged twenty-six years to forty-five years and thereafter it declined. This is not easily comparable with studies from other settings that enrolled older populations greater than thirty years. These studies reported that higher perceived risk is correlated with younger (28–30). However, it is important to note that in most developing countries cancer of the breast tends to occur in younger women below the age of 50 years unlike the case in most developed countries where the incidence of breast cancer is higher in women aged beyond 50 years (31). Younger women in the low- and middle-income countries need to be aware that they are at risk of developing breast cancer and therefore encouraged to undertake appropriate risk-reduction and early detection measures.

In this study, the most practiced preventive behavior was a self-breast examination and the least utilized modality was mammography. Low uptake of mammography may be a result of several factors including lack of access to the services, high costs, and low knowledge about the service (32). For some developed countries, it is recommended that individuals at an elevated risk for breast cancer start mammographic screening earlier and have supplemental screening modalities (10). However, in most resources limited setting such services are simply not available and the cost of providing them is extremely prohibitive especially in the context of other competing demands. Thus, it is not surprising that an exceedingly small proportion of the participants had ever had a mammogram done. Although the benefit of proving large-scale mammography screening in less developed countries is open to debate (33), perhaps modalities should be developed for providing such services to the most at-risk populations such as FDRs.

## Limitations

Our study had some limitations. First, we were not able to achieve our computed sample size because of the difficulties we encountered in recruiting participants. For example, first-degree relatives staying beyond the 40 Km radius from the study site were unable to travel to the study site to participate in the study. The study team made efforts to amend the protocol to have these enrolled in the study through telephone interviews, which was declined given the risk of the study. However, we believe that with the sample used, the study was powered enough to allow us to detect differences between the groups. Second, this was a cross-sectional study; we could not dissect to establish at what point the self-

perceived risk changed even though we restricted the participants to compare since when the index patient was diagnosed. Participants could have simply stated their current perceptions which are influenced more by the sight of the multitude of breast cancer patients rather than just their relatives.

## **Conclusion**

The majority of the participants perceived themselves to have a low likelihood of developing breast cancer in their lifetime and did not practice risk reduction measures even though they had biological relatives with breast cancer. The older women were more likely to perceive themselves to be at higher risk of developing breast cancer compared to the younger women. Breast cancer health education with an emphasis on risk factors including being a first-degree female relative to a breast cancer patient is a necessary though not sufficient intervention to improve uptake of risk reduction measures and reduce the incidence of breast cancer.

## **Abbreviations**

BSE Breast Self- Examination

CBE Clinical Breast Examination

FDRs First Degree Relatives

GLOBOCAN Global Cancer

## **Declarations**

### **Ethics approval and consent to participate:**

The study was approved by the Uganda Cancer Institute Research Ethics Committee (#UCIREC-REF-19-2017) and Uganda National Council of Science and Technology (HS277ES). Informed consent was sought from all participants after a clear explanation was provided about the objectives of the study, risk factors, and the benefits. Confidentiality and privacy were observed during the conduct of the interviews. The identification numbers were used to identify participants instead of their names. All study procedures were performed in accordance with Good Clinical Practice, National and International guidelines and regulations for the conduct of research.

### **Consent for publication:**

Not applicable. The manuscript does not contain any personally identifiable data.

### **Availability of data and materials:**

The datasets used and/or analyzed during the current study are available from the corresponding author on a reasonable request.

## Competing interests:

Authors declare that there are no competing interests.

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## Authors' contributions

PA, DBA, CPO, and ADM conceptualized the study, participated in writing the protocol, interpreted the results, and reviewed the manuscript.

PA and DBA acquired regulatory approvals, supervised data collection, and drafted the manuscript.

GA, AP, and ADB conducted data analysis and interpreted results.

GM and IM participated in the supervision of data collection and reviewed the final manuscript.

All authors read and agreed on the final manuscript.

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