COMPARING WOMEN'S UNPROMPTED AND PROMPTED KNOWLEDGE OF BREAST AND CERVICAL CANCER RISK FACTORS AND SYMPTOMS IN SUB- SAHARAN AFRICA

By

Trish Muzenda (MZNTRI001)

Supervisor: Professor Jennifer Moodley

Co-supervisor: Dr Deborah Constant

Submitted: February 2019

A mini-dissertation submitted to the School of Public Health and Family Medicine, Faculty of Health Sciences, University of Cape Town in partial fulfilment of the requirements for the award of the degree of Master of Public Health (Epidemiology and Biostatistics Specialisation)

Cape Town, 2019.

Plagiarism Declaration

This thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software) and I confirm that my supervisor has seen my report and any concerns revealed by such have been resolved with my supervisor."

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TRISH MUZENDA

Date: 9 February 2019

PART 0: PREAMBLE

DEDICATION

To my loving Aunt and Uncle, I cannot thank you enough for all the support and encouragement you have given me. I never would have made it here without you.

ABSTRACT

Breast and cervical cancer are leading causes of female cancer morbidity and mortality in Sub-Saharan Africa (SSA). Despite the high burden of disease, women's knowledge of evidence-based risk factors and symptoms remains low. To adequately address the apparent knowledge deficits, the underlying knowledge in communities needs to be measured, so as to identify important gaps and contextually address them. To date, cancer knowledge in SSA has been measured using either prompted or unprompted question formats, yielding varying knowledge scores. However, there has been little exploration on the impact of using either question format for assessing disease awareness. This study sought to measure the differences in breast and cervical cancer risk factors and symptoms knowledge reported through prompted and unprompted questions, in South Africa (SA) and Uganda (UG).

This was a descriptive cross-sectional study drawing on data collected during validation of an interviewer administered questionnaire (African Woman's Awareness of Cancer - AWACAN) measuring breast and cervical cancer awareness in SSA. The sample included 139 women recruited from public sector primary health care facilities in two urban districts, Gulu (UG) and Cape Town (SA). Descriptive statistics were used to summarize participant's socio-demographic characteristics and knowledge about breast and cervical cancer. Composite knowledge scores were calculated by adding up the number of correct responses per individual. The Wilcoxon Singed Rank test was used to compare differences between unprompted and prompted knowledge scores. Regression analyses were used to measure the relationship between unprompted and prompted knowledge.

The median age of study participants was 42 years. The majority of women had not completed secondary education (57%) and were unemployed (64%). Unprompted knowledge was considerably lower than prompted knowledge for all breast and cervical cancer risk factors and symptoms. Median scores for unprompted knowledge of breast cancer risk factors (0) and symptoms (1) were significantly lower than for prompted at 6 and 14 respectively. Similarly, the median scores for unprompted knowledge of cervical cancer risk factors (0) and symptoms (1) were lower than prompted knowledge at 6 and 9 respectively. The difference between prompted and unprompted knowledge was least for

classical breast and cervical cancer symptoms. For instance, the well-known breast cancer symptom 'lump in the breast' was recalled by 57% and 96% with unprompted and prompted questioning respectively. Unprompted questioning identified additional risk lay beliefs such as, 'itching of the breast'.

Combined use of unprompted and prompted questions provides more insight on breast and cervical cancer knowledge patterns in SSA. The low unprompted knowledge scores reported here demonstrate the need for health education interventions to improve knowledge of established breast and cervical cancer risk factors and whilst addressing any predominant lay beliefs about the disease in SSA.

This dissertation is divided into three parts. Part A consists of the study protocol outlining the rational for undertaking this study as well as the proposed research methodology. Part B is the literature review that gives a summary of existing literature on the use of prompted and unprompted questions in measuring cancer knowledge thereby providing context for this study. Part C is a journal ready manuscript presenting the results and discussion of study findings.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank the Lord Almighty for giving me the knowledge, strength and opportunity to undertake this research study and complete it. Through your grace, all things are possible.

I would like extend a heartfelt thank you to my supervisor Professor Jennifer Moodley for giving me the opportunity to undertake this project under the main ongoing study. Thank you for your continued support, guidance and patience throughout this journey. I am deeply thankful for the opportunity you gave me to attend modules at the University of Cambridge, visit the Lusikisiki research site as well as being involved in various research activities in the main study. This has given me a solid foundation as I embark on my career in public health research.

To my co-supervisor, Dr Deborah Constant, I am so thankful for your support and guidance throughout this project. You taught me so much on the application of quantitative research methods to answer public health research questions.

I extend many thanks to the Newton Project Team; Dr Fiona Walter, Dr Suzanne Scott, Dr Jennifer Githaiga and Dr Amos Mwaka, for their intellectual input throughout this study.

I express my deepest gratitude to my friends and family. Thank you for your unwavering belief in my abilities, and for helping me stand strong throughout this journey.

Lastly, I would also like to extent my gratitude to the Cancer Association of South Africa (CANSA), the University of Cape Town, the South African Medical Research Council, the South African National Department of Health, GlaxoSmithKline R&D, the UK Medical Research Council and the UK Government's Newton fund for funds awarded towards my Masters of Public Health dissertation.

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PART A: PROTOCOL

Comparing women's unprompted and prompted knowledge of breast and cervical cancer risk factors and symptoms in Sub- Saharan Africa

BACKGROUND

Breast and cervical cancer are leading causes of cancer morbidity and mortality amongst women worldwide. [1] In 2018, breast cancer accounted for 26% of the total female cancer incidence in Sub-Saharan Africa with age standardised incidence rates (ASIR) ranging from 28 to 46 new cases per 100000 people. [2] Breast cancer incidence is associated with increased prevalence of risk factors such as, aging and smoking. [3] Cervical cancer contributed 23% towards the female cancer incidence in Sub-Saharan Africa with an ASIR ranging from 27 to 43 per 100000 of the population (world). [2] Cervical cancer is also the leading cause of female cancer deaths in 36 countries in the region. [2] The high cervical cancer incidence rates experienced in Sub-Saharan Africa (SSA) are driven by prevalence of the causative agent – Human papillomavirus (HPV) and risk factors such as parity. [3,4] The high mortality rates for both breast and cervical cancer are driven by late presentation of patient symptoms and limited health services in the region. [3,5-8] Given the high disease burden, there is a need for health education interventions to improve breast and cervical cancer prevention and control strategies in the region.

The majority of breast and cervical cancer cases in SSA are diagnosed at a late stage (Stages III and IV) when disease prognosis is poor. [7, 9-10] Further to this, late stage diagnosis is, partially, a result of delayed presentation of symptoms at healthcare facilities. It is suggested that some women present late for healthcare because they may be unaware of their risk for breast or cervical cancer and/or the gravity of their symptoms. [11-13] In light of this, it is important for health awareness initiatives to work on improving breast and cervical cancer knowledge in women at increased risk of disease. [14] In order to develop evidence-based interventions for the timely diagnosis of breast and cervical cancer, it is imperative to first understand women's knowledge and perceptions of these diseases. [15]

Women's knowledge of breast and cervical cancer can be measured using prompted or unprompted questions. [16] Prompted questions measure an individual's ability to remember information from memory given multiple cues in the present and limited response options. [16-17] These questions are useful when trying to obtain specific information, for example recognition of breast cancer symptoms, or when asking respondents whether they agree or disagree with an opinion.[16] Additionally, the limited responses provide information that is easily quantifiable during data analysis. Despite these advantages, results from prompted questions need to be interpreted with caution since they are more prone to issues of guessing and they limit the respondent's ability to give answers reflecting their true knowledge on a topic. [16, 18]

Unprompted questions assess an individual's ability to remember information from the past given limited or indirect cues in the present. [16, 17] Unlike prompted questions, unprompted questions offer the participant an opportunity to express their opinions without forcing them to select from pre-determined answers. [17] This is an advantage in that respondents provide unanticipated responses that would have otherwise been missed using prompted questions. However, unprompted questions in surveys often have low response rates owing to the fact that participants may need more time and mental effort to come up with an answer than is allocated in surveys.[16]

Findings from cross-sectional studies assessing breast and cervical cancer awareness in Sub-Saharan Africa indicate poor to moderate knowledge of disease risk factors and symptoms depending on the question format used.[10,13,16,19] Generally studies using prompted questions, such as 'Do you think smelly vaginal discharge is a sign of breast cancer', tend to report better knowledge scores than those using unprompted questions, such as 'Do you know any cervical cancer symptoms'. [10,13,16,19] For example, a Cameroon study found that less than 35% (N=225) of women had unprompted knowledge of key breast cancer risk factors such as age, family history and oral contraceptive use.[20] In contrast,

a South African study using prompted questions reported that at least 69% of women correctly identified each of the risk factors listed in the questionnaire.[10]

In studies, where prompted and unprompted question formats are used concurrently, prompted responses consistently relay better knowledge scores than unprompted responses. [16-18, 21] For example, evidence from a cross sectional study measuring awareness for lung cancer found that difference between prompted and unprompted knowledge of risk factors was least amongst those aged above 40 years compared to those below.[22] This pattern of higher knowledge scores in prompted questioning is associated with factors such as, age, education, information familiarity and the source of information. [16-18, 21] For example, a recent study measuring breast cancer knowledge found that most women (>70%) identified the classical symptom 'breast lump' with both prompted and unprompted questions but a lesser known symptom 'change in nipple position' was identified by only 5% with unprompted questions compared to 86% with prompted questions. [10]

From the above synopsis, the use of either prompted or unprompted questions can influence subsequent breast or cervical cancer knowledge scores. Given this, it is important to explore the value of using either unprompted or prompted questions when measuring breast and cervical cancer knowledge in SSA. This information will be useful in the design and evaluation of public health interventions seeking to measure and improve breast and cervical cancer knowledge in the region. Therefore, this study aims to measure the differences in breast and cervical cancer knowledge reported through prompted and unprompted questions in South Africa (SA) and Uganda (UG).

Research Question

Is there any difference between unprompted and prompted knowledge of breast and cervical cancer risk factors and symptoms among women in South Africa and Uganda?

Hypothesis

Null hypothesis: There is no difference between unprompted and prompted knowledge of breast and cervical cancer risk factors and symptoms.

Alternate hypothesis: Unprompted knowledge of breast and cervical cancer risk factors and symptoms is lower than prompted knowledge.

Research Objectives

The objectives of this study are:

- To describe women's unprompted and prompted knowledge of established breast and cervical cancer risk factors and symptoms
- To quantify the effect of prompting on the knowledge of risk factors and symptoms of breast and cervical cancer.
- To describe common breast and cervical cancer lay beliefs.

METHODS

Research design

This will be a descriptive cross-sectional study drawing on data collected during psychometric testing of the African Woman's Awareness of Cancer - AWACAN (previously known as the African Breast and Cervical Cancer Symptom Awareness - ABCCSA) questionnaire. The validated AWACAN tool was developed under the parent project – Improving timely diagnosis of breast and cervical cancer in Sub-Saharan Africa – to measure the overall awareness for breast and cervical cancer in Sub-Saharan Africa. Detailed methodology for AWACAN tool development and validation is described elsewhere in detail. [23] The AWACAN English Version 1.7 used for this study is attached under **Appendix 1**.

Study population

The study population in the parent study included English-speaking women aged above 18 years residing in one urban site in South Africa (Khayelitsha) and one urban site in Uganda (Gulu). Population characteristics are described in **Table 1** below.

Table 1: Population characteristics for South Africa (Khayelitsha) and Uganda (Gulu).

Characteristics	Khayelitsha, South Africa	Gulu, Uganda
Population	391 749	152 276
Literacy rate	80%	64%
Age-standardised incidence* of breast cancer	49.0	21.3
Age-standardised mortality* of breast cancer	16.3	10.3
Age-standardised incidence* of cervical cancer	43.5	54.8
Age-standardised mortality* of cervical cancer	19.2	40.5

*age standardised rate per 100000 of the world population

Sample size estimation

The sample size during psychometric testing of the AWACAN tool was estimated as required for internal reliability validation of the tool. Internal reliability is calculated of the assumption that the number of respondents should exceed the number of items by 2 to 20 subjects per item, with a minimum of 100 subjects to ensure stability of the variance-covariance matrix. The sample size was based on a 120-item (60 breast and 60 cervical cancer) questionnaire, with 180 participants (including University of Cape Town non-academic staff, community participants and cancer experts), Cronbach alpha cut off of 0.7 and Type I error rate of 5%. The current study will use available data collected from community participants (n=139) during the validation process.

Sampling and recruitment strategy

In the parent study, community participants were approached at public primary health care facilities within the two study sites to take part in the study. The inclusion criteria for participation in the study was as follows: women aged above 18 years, either first or second language English speaker with no previous breast or cervical cancer diagnosis. Potential participants were screened based on the

inclusion criteria. If interested, more information about the study was provided and willing participants were asked to sign the consent form before taking part in the interview. Study participants were recruited until an equal number of women aged above and below 50 years were interviewed to capture knowledge of women at risk for breast and cervical cancer. In total, 139 women were recruited for participation in the parent study.

Data collection

AWACAN questionnaire

Items in the AWACAN tool were generated by reviewing pre-existing cancer awareness measurement tools, Cancer Awareness Measure (CAM) and Awareness and Beliefs about Cancer (ABC), and relevant literature from African Studies.[23] In the questionnaire, the general format for unprompted questions read "Please could you name any signs or symptoms of breast (or cervical) cancer as you can think of?" Prompted questions asked – "Can you tell me if you think the following could be signs of something serious or that something is wrong such as breast (or cervical) cancer". Three response options (Yes, No and I don't know) were given for prompted questions. To address potential recall bias, unprompted questions are presented before prompted questions.

The AWACAN tool collected information on:

- Participant sociodemographic characteristics: age, marital status, education, employment and housing.
- Knowledge of 13 established breast cancer risk factors: having had breast cancer previously, drinking more than 1 unit of alcohol per day, using hormone replacement therapy, using family planning methods, being overweight, having a family member with breast cancer, having the first child after the age of 30 years, having no children at all, starting your periods early, before the age of 11 years, having menopause late after the age of 55 years, doing little physical activity, aging, and not breastfeeding.

- Knowledge of 15 breast cancer symptoms: a change in the position of the nipple, pulling in of the nipple, a change in the size of the nipple, a change in the shape of the nipple, nipple rash, discharge from the nipple, bleeding from the nipple, pain in one or both breasts, a lump or thickening in the breast, a change in colour of the breast, puckering or dimpling of the breast skin, a change in the shape of the breast, a lump or thickening under the armpit, pain in the armpit.
- Breast cancer risk factor lay beliefs: being exposed to dirty air, wearing a tight bra, wearing a bra all the time, putting money in one's bra, putting a mobile phone in one's bra, being bewitched/witchcraft and stress.
- Knowledge of 10 cervical cancer risk factors including: HPV infection, HIV/AIDS, other STI infections, using birth control pills for more than 5 years, cigarette smoking, having an uncircumcised sexual partner, having sex at a young age, giving birth to three or more children, having many sexual partners, not going for regular screening for cervical cancer.
- Cervical cancer risk factor lay belief: Being bewitched/witchcraft.
- Knowledge of 11 cervical cancer symptoms: vaginal bleeding between periods, persistent lower back pain, a persistent smelly vaginal discharge, discomfort or pain during sex, menstrual periods that are longer or heavier than usual, persistent diarrhoea, vaginal bleeding after menopause, persistent lower abdominal pain, vaginal bleeding during or after sex, blood in urine or stool, unexplained weight loss.

Interviews

Female interviewers, with a minimum secondary education and fluent in English, were trained on recruiting and interviewing study participants. During interviews, interviewers read out questions from the AWACAN tool and recorded participant responses on the paper-based questionnaire. Completed questionnaires were cross checked by the study co-ordinator and interviewer at the end

of each field day. Collected information was captured electronically onto Qualtrics software for future analysis.

Data Analysis

Coding unprompted responses

Free text responses to unprompted questions will be grouped using deductive coding. First, responses will be reviewed to get a sense of the data. Next keywords or phrases generated from known risk factors and symptoms will be identified. For example, a keyword "lump" could be used to identify responses mentioning the breast cancer symptom "lump in the breast". These keywords or phrases will subsequently be used to group all responses. Additional groups will be generated for free text responses that are not similar to known risk factors and symptoms. Once all responses have been assigned to a group, group allocations will be reviewed and discussed by a research team with expertise in qualitative and quantitative data analysis until consensus is reached. To allow for comparison between prompted and unprompted knowledge scores, each recalled symptom (corresponding to those listed in the AWACAN tool) will be scored '1'. A score of '0' will be allocated for each risk factor not mentioned by a participant in unprompted questioning.

Coding of prompted responses

During prompted questioning, participants were presented with three response options "Yes", "No" and "I don't know". The "Yes" response will be scored 1. 'No' and 'I don't know' will be scored 0 to indicate lack of knowledge.

Coding of breast and cervical cancer lay beliefs

In prompted questioning on breast and cervical cancer lay beliefs, participants were presented with three response options "Yes", "No" and "I don't know". The "Yes" response will be scored '1' whilst "No'" and "I don't know" will score '0'.

Generating composite knowledge scores

- *Unprompted knowledge of evidence-based risk factors and symptoms*

A composite score for unprompted knowledge will be generated for each participant in these categories: breast cancer risk factor knowledge, breast cancer symptom knowledge, cervical cancer risk factor knowledge and cervical cancer symptom knowledge. For ease of comparison, unprompted recall of each breast (or cervical) cancer risk factor or symptom listed in the AWACAN questionnaire will be scored '1'. Therefore the maximum possible unprompted knowledge scores for each category will correspond to the number of risk factors listed in the prompted section AWACAN tool.

- *Prompted knowledge of evidence based risk factors and symptoms*

Composite knowledge scores for each participant will be generated for each of the following categories: breast cancer risk factor knowledge, breast cancer symptom knowledge, cervical cancer risk factor knowledge and cervical cancer symptom knowledge. Each correct response (Yes) to a prompted question will be allocated a score of 1 and incorrect answers (No, I don't know) will score 0. The total number of correct responses, from each participant, will be added up to give the composite score. The maximum possible composite knowledge scores in each category (breast cancer risk factors - 13, breast cancer symptoms - 15, cervical cancer risk factors- 10 and cervical cancer symptoms- 11) will correspond to the number of risk factors and symptoms listed in the AWACAN tool.

Descriptive statistics

The socio-demographic characteristics, risk factors, symptoms knowledge of study participants will be summarized. The mean, standard deviation, median and inter-quartile range will be used to describe continuous variables. Categorical variables will be summarized using proportions and 95% confidence intervals.

Comparing composite knowledge scores

For bivariate analysis of unprompted and prompted composite knowledge scores, the Student's t-test will be used to compare means, Wilcoxon signed rank tests will be used to compare medians. Statistical significance will be indicated by p-values less than 0.05.

Regression Analysis

A logistic regression model will be used to calculate the odds of recalling each risk factor and symptom in prompted questioning compared to unprompted questioning. For this model, unprompted knowledge will be the independent variable, whilst prompted knowledge will be the dependent variable. Prior to computing linear regression models, the Spearman's correlation coefficient will be used to check for a linear relationship between unprompted and prompted variables. Thereafter, linear regression models will be computed to describe the linear relationship between unprompted and prompted composite knowledge scores for each of these categories; breast cancer risk factor knowledge, breast cancer symptoms knowledge, cervical cancer risk factor knowledge and cervical cancer symptoms knowledge. Post-regression diagnostics tests will be conducted to check whether there are any violations in the regression model assumptions or if there are any issues with the data. Specifically, we will use the regression models Adjusted R^2 value to measure goodness of fit of each model, Quantile-quantile plots to check if residuals are normally distributed and lastly scatterplots of ordinary residuals versus predicted values to check for homogeneity of variance. Data will be analysed using STATA Version 14 software.

Ethical considerations

The parent project – Improving timely diagnosis of symptomatic breast and cervical cancer in Sub-Saharan Africa – received ethical clearance from the Faculty of Health Sciences Human Research Ethics Committee of the (University of Cape Town) (Reference number – 544/2016), Uganda School of

Medicine Research and Ethics Committee and the Ugandan National Council of Science and Technology (Reference number - HS60ES) prior to commencing the project.

Informed Consent

During data collection, the process of consenting involved an in-depth verbal description of the study information sheet followed by signing of the consent form. Participation in the parent study was voluntary and participants were not forced or put under undue influence. Participants were allowed to opt out of the study if at any point of the interview. Additionally, it was made clear to all participants that opting in or out of the study would in no way impact on their treatment in the health care centre. Once enrolled into the study, all participants were given a non-identifying code noted on their consent form. Consent forms were stored away from the completed questionnaires so as to maintain the privacy of study participants.

Confidentiality

Completed questionnaires were stored in secure locked filing cabinets, with access limited access to the project coordinator and principal investigator. Each participant was allocated a distinctive participant ID which was used for data capture into the study database. Electronic data was stored on password protected computers with access limited to the core investigators in the study. Consent forms linking participant ID to participant name were stored in a separate database accessible only by the study coordinator. Confidentiality was upheld at all times in the study ensuring that there were no direct personal identifiers to study participants. Future publications and presentations produced from the project will not identify any of the study participants.

Risk and benefits

This study will not pose any risks to study participants. Partaking in the parent study did not pose any physical risk to the participants and the communities involved in the study. After each interview,

participants were presented an information sheet detailing the major signs and symptoms of breast and cervical cancer in English. Participants wanting more information or on breast and cervical cancer were referred to health centre staff with a reference letter. It was anticipated that by taking part in the study, women would be more aware on breast and cervical cancer symptoms. Information received in this study will aid towards designing of interventions that seek to improve the timely diagnosis of breast and cervical cancer in sub-Saharan Africa.

BUDGET

This research is supported by CANSA; the University of Cape Town, and; the South African Medical Research Council with funds received from the South African National Department of Health, GlaxoSmithKline R&D, and the UK Medical Research Council and with funds from the UK Government's Newton fund. Access to bibliographic references, scientific support and supervisions will be provided by UCT as part of its Master of Public Health degree programme.

TIME FRAME

This study is projected to take 7 months as shown below

Component	**Date**
Ethics paper work; Project proposal draft; Final proposal hand in	August 2018
Literature search	September 2018
Literature review write up	October 2018
Data analysis	October – November 2018
Writing of manuscript	November 2018 – January 2019
Final thesis preparation	January - February 2019
Submission of dissertation and dissemination of findings	February 2019

DISSEMINATION OF RESEARCH FINDINGS

The proposed study will be submitted in partial fulfilment of the requirements for the Master of Public Health (Epidemiology and Biostatistics) degree at the University of Cape Town.

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PART B: LITERATURE REVIEW

Comparing women's prompted and unprompted knowledge on breast and cervical cancer risk factors and symptoms in Sub-Saharan Africa

OBJECTIVES

The main objectives of this literature review are:

- To describe the burden of breast and cervical cancer in Sub-Saharan Africa
- To describe women's knowledge on breast and cervical cancer in Sub-Saharan Africa
- To discuss measurement of knowledge using prompted and unprompted questions
- Identify gaps in the literature on unprompted and prompted measurement of breast and cervical cancer knowledge.

LITERATURE REVIEW SEARCH STRATEGY

The literature review search was conducted in the following databases; Africa-Wide Information, PubMed, SCOPUS, PsycARTICLES and Web of Science. Key words used in the search included "cancer OR breast cancer OR cervical cancer "AND "knowledge OR awareness OR mental recall" AND "risk factor OR symptom OR signs and symptoms" AND "prompted questions OR close ended questions OR multiple-choice questions" AND "unprompted questions OR opened ended questions". Additionally, literature comparing prompted and unprompted knowledge was sought in the above mentioned databases. Abstracts were screened based on key words. Thereafter, selected articles were inspected for relevance. Reference lists from selected literature were examined to obtain additional unidentified journal articles. There were no limitations on publication dates.

BREAST AND CERVICAL CANCER BURDEN

Breast and cervical cancer contribute immensely towards the female cancer burden of disease in low income (LIC) and lower-middle income countries (LMIC). [1] In 2018, approximately 3 576 656 new cancer cases were diagnosed in these two regions, of these 27% and 15% were attributable to breast and cervical cancer respectively. [2] The age standardized incidence rates (ASIR) for breast cancer in LIC and LMIC was 31 per 100 000. [2] Cervical cancer ASIR was pegged at 18 per 100 000. [2] In addition to these high incidence rates, breast and cervical cancer contribute 21% and 16% towards female cancer mortality in LIC and LMIC. [2] In Sub-Saharan Africa (SSA), breast cancer incidence varies with ASIR ranging from 28 to 46 per 100000. Cervical cancer ASIR ranges from 27 to 43 per 100 000. Of note, cervical cancer was the leading cause of female cancer death in 36 countries in SSA. [1,2] Based on this evidence, that breast and cervical cancer are diseases of public health importance and comprehensive prevention and control interventions are needed in SSA. [1,3]

Breast cancer incidence in SSA mirrors the distribution of risk factors. [4] Incidence rates are highest in urban areas were lifestyle associated risk factors, such as reduced physical activity, changes to dietary habits and having children late (**Table 1**), are more prevalent. [4] Breast cancer mortality in SSA differs across countries due to disparities in health service delivery, knowledge and health seeking behavior.[5,6] The availability of screening procedures, including clinical breast examination and mammography, provide for early diagnosis and subsequent treatment. [7] However, there are limited breast cancer screening programs in SSA and most cases are diagnosed when women present with symptoms. [4,6] This lack of screening resources is further compounded by limited knowledge of symptoms among women. [8,9,10] Thus, women in LMIC present with advanced breast cancer (Stages III and IV) which is associated with poor prognosis. [11]

The high cervical cancer incidence in SSA is driven by the high prevalence of the causative agent of cervical cancer - Human Papillomavirus (HPV) [12], and other established risk factors such as Human Immunodeficiency Virus (HIV) and parity. [13-15] The World Health Organization (WHO) recommends

HPV vaccination for primary prevention of cervical cancer and Pap-smear screening (for cervical precancerous lesions) as secondary prevention. [16] Unfortunately, most SSA countries are unable to implement effective vaccination and screening programs due to the financial, infrastructural and human resource requirements to set up such initiatives. [17] Additionally, in some settings where services are available, screening uptake may be low, owing to lack of knowledge on the importance of screening as well as the link between HPV and cervical cancer. [18-20] Because of this, as described with breast cancer, cervical cancer mortality is high in SSA owing to limited screening and late stage presentation of symptoms. [21]

Improving the timely diagnosis of cancer in developing regions is complex due to a host of reasons, such as lack of resources and competing public health needs. [6, 19] However, evidence from High Income Countries (HIC) shows that if diagnosed and treated early, breast and cervical cancer cases have a better prognosis. [22-24] Hence it is important for health organizations to invest in culturally relevant ways to improve screening and early diagnosis of symptomatic breast and cervical cancer in SSA. This can be done by raising awareness of disease in communities, particularly to individuals at high risk. [4] Evidence shows that knowledge is an important precursor to proximal predictors of health seeking behavior including attitudes, subjective norms and perceived individual risk. [25-27] Therefore, improving breast and cervical cancer knowledge could positively impact health seeking behavior. [26-27]

BREAST AND CERVICAL CANCER KNOWLEDGE IN SUB-SAHARAN AFRICA

Knowledge of established breast [28] and cervical [29] cancer risk factors and symptoms (**Table 1-4**) is low in SSA. [30-40] Cross-sectional studies conducted in Zimbabwe, South Africa, Cameroon, Tanzania, Nigeria and South Africa indicate that although women have heard of breast cancer, most are not aware of the associated risk factors or symptoms. [30-35] Findings from Zimbabwe (>50%, *N*=120), Tanzania (60%, N=225), Nigeria (26%, N=214) and South Africa (25%, N=201) show that family history,

alcohol use and smoking are the most commonly recognized as a breast cancer risk factors by women in SSA. [30-31, 35] Knowledge of other reproductive and menstruation related risk factors (**Table 1**) is poor in these settings. [30-35]

Table 1: Established breast cancer risk factors [28]

	Factor grouping	Risk factor
Breast cancer	Reproductive	Use of contraceptives
		Not breast feeding
		Having no children
		Having children late (after 30 years)
	Menstruation	Starting periods at less than 12 years
		Starting menopause late (after 55 years)
		Use of hormone replacement therapy
	Lifestyle	Consuming more than more than 1 unit of alcohol per day
		Lack of exercise
		Being overweight
		Stress
	Other	Aging
		Personal history of breast cancer
		Family history of breast cancer

Cultural beliefs, such as placing money in a bra and evil spirits were also mentioned by a majority of women in Zimbabwe (>70%) and Tanzania (80%) as causes for breast cancer. [30-31] The general poor knowledge of major risk factors compared to community beliefs is concerning as this can mislead women into harmful disease prevention practices.

With regards to symptom knowledge, a Nigerian cross-sectional survey on breast cancer awareness found that only 21.4% of women could identify a breast lump as a breast cancer symptom and even fewer (<20.0%, N=214) participants knew of non-lump symptoms such as nipple discharge and pain in the breast. [9] Similarly, another study found that 80.6% of South African women (N=299) could not identify any breast cancer symptoms, and of those that could, only 18.4% % mentioned the breast lump. [34] However, a more recent cross-sectional study conducted in South Africa showed encouraging results as most participants were aware of breast cancer and correctly identified (>76%, N= 201) a lump in the breast or armpit as signs for breast cancer. [35]

Table 2: Established breast cancer symptoms [28]

	Site	Symptom
Breast cancer	Breast	Lump
		Pain in breast(s)
		Change in colour of breasts
		Change in shape of breasts
		Puckering or dimpling of the breast skin
		Change in breast size
	Nipple	Nipple rash
		Nipple discharge
		Bleeding from nipple
		A change in the position of the nipple
		Pulling in of the nipple
		A change in the size of nipple
		A change in the shape of nipple
	Armpit	Pain under the arm
		A lump or thickening under the armpit/underarm

General knowledge of cervical cancer risk factors and symptoms varies across the SSA region. [37-40] For instance, more than 70% of women in Ethiopia (N=633), Botswana (N=289), and Gabon (452) reported having some knowledge about cervical cancer, but in Nigeria, only 4.2% (N=240) had knowledge of the disease. [37-40] Among had some knowledge of cervical cancer, 54% in Botswana, 78% in Gabon and 69% in Ethiopia were unable to mention at least one risk factor. [37-39] Sexual intercourse related risk factors such as early sexual debut, unprotected sex, STI (including HIV) and multiple sexual partners are commonly cited as risk factors among those with knowledge of established risk factors. [37-39, 41] Several cervical cancer risk factor beliefs, such as insertion of foreign objects inside the vagina, abortion, poor hygiene and being bewitched are cited, at varying proportions in literature. [42]

Table 3 Established cervical cancer risk factors [29]

	Factor grouping	Risk factor
Cervical cancer	Infection	HPV infection
		HIV/AIDS
		Other Sexually transmitted infections
	Reproduction	Using contraceptives for more than 5 years
		Early sexual debut (less than 17 years)
		Giving birth to more than 3 children
	Lifestyle	Many sexual partners
		Smoking
	Other	No regular screening

A Ugandan cross-sectional study investigating cervical cancer awareness reported high awareness (>70%, N=448) of cervical cancer symptoms (e.g. vaginal bleeding, post-menopausal bleeding, smelly vaginal discharge and abdominal pain). [41] On the other hand, awareness of symptoms was poor among Ethiopian women with only two symptoms (smelly discharge and excessive discharge) being mentioned by at least 30% (N= 633) of participants. [37] Other symptoms such as pain after sex were unknown. These discrepancies in knowledge could be the result of differing public health priorities and cultural norms between the two countries.

Table 4: Established cervical cancer symptoms [29]

	Site	Symptom
Cervical cancer	Vagina	Vaginal bleeding after menopause
		Persistent smelly discharge
		Discomfort or pain during sex
		Vaginal bleeding during or after sex
	Menstruation	Vaginal bleeding between menstrual periods
		Menstrual periods longer or heavier than usual
	Lower abdomen/back	Lower abdominal/pelvic pain
		Persistent lower back pain
	Other	Blood in urine or stool
		Unexplained weight loss
		Persistent diarrhoea

Breast and cervical cancer awareness in SSA differ along sociodemographic lines. [30-43] Older and highly educated women tend to score better in awareness assessments compared to other groups. [36-43] Adding to this, knowledge sometimes varies by occupation with those working in the health sector displaying better understanding of disease compared to those working in trading and business. [36,39] For most countries in Sub-Saharan Africa, low awareness of risk factors and symptoms is partially a consequence of inadequate public health education efforts in raising awareness. [36] This demonstrates the need for comprehensive health education and advocacy approaches to improve awareness of established facts and address any lay beliefs. [36]

MEASURING KNOWLEDGE THROUGH UNPROMPTED AND PROMPTED RECALL

According to Wight [44] the most crucial step in designing public health interventions is to first define and understand the problem at hand. In the context of breast and cervical cancer awareness, this implies the need to first measure community knowledge and possible lay beliefs about the disease. [45] Collated evidence can then be used to identify any knowledge gaps and potentially inform future interventions. Disease awareness is commonly measured using survey questionnaires. The type of questions in surveys fall into two groups, prompted (close ended) or unprompted (open ended) questions. [46] These questions elicit prompted (recognition) and unprompted (recall) knowledge, respectively. [26] The following sections in this literature review seek to illustrate how knowledge is measured using these methods.

Prompted knowledge

Prompted knowledge refers to an individual's ability to remember previously encountered information when given multiple cues in the present. [26, 47] For instance, the ability to recall information about cervical cancer, when urged to think about specific elements of the disease. Prompted recall is predominantly measured using prompted (close ended) questions. [26] Such questions provide cues aiding the association between new and previously stored information. Prompted questions are complemented by limited response options which help guide the respondent's memory. [26, 47] Given the multiple aids, prompted recall tends to require less thought from respondents as the questions and response options are leading. [26] An example of prompted a question, as used in a South African cross sectional study on breast cancer awareness, reads, 'Can you tell me if you think a lump in the breast is a sign of breast cancer?' This question was accompanied by the following limited responses; 'Yes', 'No' and 'Don't know. [35]

Traditionally, health awareness research has favored the use of prompted questions to measure knowledge of disease risk factors and symptoms. This is because, prompted questions are highly structured and have restrictive response options making it easier for the respondent to comprehend

the subject matter. [48-50] Consequently, respondents are more likely to provide the exact information sought by the researcher. An example is shown in a Libyan study that used prompted questions to determine respondents' (N=412) ability to recognize 11 cervical cancer symptoms given three response options 'Yes', 'No' and 'I don't know'. [51] During data analysis, the three response options were each allocated a numerical code and categorized into groups for further analysis. The 'Yes' response was allocated a score of '1' to indicate correct knowledge of a risk factor whereas 'No' and 'I don't know' were scored '0' representing lack of knowledge. [51] This conversion of responses is particularly useful when assessing the statistical significance of survey results and comparing responses across the study population.

The static nature of responses to prompted questions can be a disadvantage as this hinders the respondent's ability to give answers reflecting their true opinions on a topic. [49] Consequentially, the researcher also misses out on unanticipated information. [49] To try and mitigate this, some health-related questionnaires include sections asking respondents to provide any additional information they would like to discuss. For example, a Norwegian study used close ended questions complemented by Likert scale response options when investigating patient perceptions of healthcare quality in hospitals. [64] For each question, respondents were urged to provide reasons for their responses. Another option often used in health awareness surveys, is to first ask open ended questions on the subject to obtain the respondents true opinion and thereafter ask close ended questions. [26,50]

One of the major pitfalls in using prompted questions to measure cancer knowledge is correct guessing of answers. [52] This is because, as discussed, prompted questions are leading and provide multiple clues for respondents to identify the correct answer. This notion was clearly illustrated by a South African study reporting limited knowledge of eleven breast cancer symptoms amongst participants despite all symptoms being recognized by at least 69% via prompted questioning. [35] Given leading questions such as 'Can you tell me if you think a lump in the breast is a sign of breast cancer', there is a possibility that some participants simply guessed the correct answer as having a

lump anywhere on the body is commonly attributed to disease. As a result, it is widely acknowledged that in some instances prompted questioning provides inflated knowledge indicators. [26,50]

To reduce chances of guessing, distractor items can be added to questionnaires, where distractors are incorrect statements that may seem correct to those who do not fully understand the concept being measured but are clearly incorrect for those with full understanding. [54,56] Distractors serve the purpose of diverting the participant from the correct answer [54, 55] and in health surveys, they are often presented in the form of plausible common lay beliefs. For example, Cournoyer [58] included a distractor – muscle spasms in the neck - in a questionnaire assessing knowledge of symptoms of concussions amongst high school football players. [58] Although incorrect, 24% of players could have identified this distractor probably because of the common lay belief that a brain injury could cause muscle spasms in the body. [58]

Unprompted knowledge

Unprompted knowledge involves remembering information/facts stored in memory given limited or indirect cues in the present. [59-60] In survey questionnaires unprompted knowledge is primarily assessed through unprompted (open-ended) questions without any preconceived response options. This allows the responder to give their own opinion on a topic. [58] Responses to open ended questions are often in the form of short phrases describing the respondent's thoughts. An example of an unprompted question used in assessing breast cancer awareness read 'Can you name as many risk factors of breast cancer that you can think of'. [35]

A key benefit to using unprompted questions is that they give the responder an opportunity to describe their own views and opinions about a topic without any preconceptions. [60] This produces qualitative open responses providing more insight compared to close-ended responses. This advantage was clearly demonstrated in a Togolese study exploring knowledge of cancer risk factors. [62] Participants were first asked about their beliefs on cancer risk factors and thereafter asked to

identify risk factors from a list of 10 established risk factors. [62] Only two of the established risk factors, alcohol use and smoking, were mentioned by participants in unprompted questioning. Rather, most participant's mentioned unanticipated cultural beliefs such as use of illegal drugs, placing money or mobile phones in bras and prostitution as risk factors. If the questionnaire had only included close-ended questions on risk factors, these unexpected beliefs would not have been reported. [60,63]

The opportunity for participants to present new information in unprompted questioning also leads to identification of new themes related to the topic of interest. [49, 63] In qualitative research, unprompted questions are used as a basis to facilitate discussion around a topic. From the discussion, the researcher picks up on various pre-conceived and new themes relating to the topic under study. [52] Likewise, unprompted questions produce open responses in the form of short descriptive phrases. Often, because responses are not guided, new themes emerge. [49] This was illustrated in a Danish survey using unprompted questions to measure patient healthcare experience [64]. Analysis of free text responses showed that, participants had not only elaborated on issues that had been brought up elsewhere in the questionnaire, but importantly new themes on patient experiences in the hospital setting were explored. [64]

Unprompted questioning requires more time and mental effort for respondents to come up with an answer [65-66]. As a result, unprompted questions generally have a lower response rate. [26, 52] For instance, in a British study assessing cancer awareness, only 48% of participants recalled a well-known risk factor 'relative with breast cancer' compared to 62% in prompted questioning. [26] The difference in these results could indicate that some participants knew the risk factor but may have required more time than was allocated in the survey to respond. Other times, participants could have an inkling on the correct answer but may be unsure. When faced with this dilemma, research shows that participants would rather state that they don't know the answer or not respond at all leading to a low

response rate. [55-56] Therefore results from unprompted questions should be analyzed with caution to avoid underestimation of true knowledge.

The wide-ranging responses obtained in prompted questioning present challenges during data analysis. [49-52] This is because open responses are neither strictly qualitative nor quantitative data hence there is no clear-cut consensus on how to deal with them during data analysis. [52]. However, for most surveys, content analysis is commonly used for data analysis. [67] During content analysis, responses are scanned for redundant and similar codes with the goal of counting and converting responses into quantifiable variables. [67] This can be a taxing exercise when responses are varied thereby yielding wide-ranging codes that are not always generalizable. [67]

Comparing unprompted and prompted knowledge

In various studies were unprompted and prompted question formats are used simultaneously, prompted questions consistently yield better knowledge scores compared to unprompted questioning. [26,47-48,61,69] For example, in 2007, a UK study found that 24.4% of 1620 women had prompted knowledge of HPV as a cervical cancer risk factor compared with only 2.5% in unprompted knowledge. [47] A later study measuring awareness of ParticipACTION (a physical activity awareness intervention) following a Canadian media campaign, also found that 8% (N=4424) of respondents had unprompted knowledge compared to 82% showing prompted knowledge. [47] Similarly, Robb [68] found that on average British women (N=1240) recalled 7.4 (out of 9) cancer symptoms when prompted compared to 2.4 without prompting. Recent evidence from a South African study measuring breast cancer awareness also showed 74% of respondents' recognized 'family history' as a risk factor for breast cancer compared to only 25% with unprompted questioning. [35]

It is hypothesized that the difference between prompted and unprompted knowledge diminishes for well-known facts. [26, 35,61] This is based on empirical evidence from Waller [26] were the effect of

prompting was minimal for the classical cancer symptom “lump/thickening” (OR [95% CI] = 2.0 (1.65-2.43]) but greatest (OR [95% CI] = 17.24[12.56-24.65]) for a lesser known symptom “sore that doesn’t heal”. A more recent study conducted in South Africa corroborates the previous assertion. When measuring breast cancer knowledge amongst 201 women, recall of the symptom ‘armpit lump’ was high for both prompted (93%) and unprompted (84%) questioning. [35] However, a lesser known symptom, ‘change in breast size’ was recognized by 92% in prompted questioning and only 10% in unprompted questioning.[35] From this evidence, unprompted recall of familiar facts could be as automatic as prompted recall since extra cues are not necessary when recalling familiar facts. [26]

Nonetheless, a British study measuring lung cancer awareness found that an acclaimed risk factor ‘smoking’ was recalled by only 12.8% (N=1484) participants without prompting compared to 85.6% when prompted. [56]. Likewise, in Libya, 51.1% of women (N=412) recalled vaginal bleeding between periods as a symptom for cervical cancer when prompted compared to 22.3% without prompting. [51] Together, these findings indicate that in some instances, the prompting effect does not hold for some well-known facts. Therefore, the concept of ‘well known knowledge’ should be approached with caution as this may differ within and across populations. [69]

The source of information (on a particular subject) may have an influence on both prompted and unprompted knowledge of the topic. [63] This was evidenced in an American survey measuring political awareness among individuals who either read news online or watched news on television. [63] In this study, prompted and unprompted questions were simultaneously used to assess knowledge of specific political information. Results showed that prompted recall of political facts was highest among those who read news online compared to those who saw it on television. [63] Conversely, people who read the news showed higher unprompted knowledge of political affairs. [63] This phenomenon, although not fully explored in health research, can be extrapolated to knowledge of cancer risk factors and symptoms. This is based on evidence showing improved cancer knowledge amongst individuals

receiving cancer information from friends or family compared to other sources such as television, radio or healthcare workers. [71-72]

The positive correlation between of level of education and disease awareness is well reported [30-36] however, less evidence is available for the association between education and the prompting effect. In theory, it is expected that the effect of prompting on disease awareness diminishes with an in increase in educational level. [26] This is based on the assumption that, highly educated individuals exhibit better knowledge hence changing question formats would not have an impact on underlying disease awareness [26]. Nevertheless, Waller [26] found that prompted questioning had a greater effect in the highly educated groups compared to less educated groups. This association was however not statistically consistent between breast cancer symptoms [OR (95% CI) = 1.53 (1.05-2.21)] and bowel cancer symptoms [OR (95% CI) = 13.21(7.86-22.20)]. Hence, these findings suggest that an association between education and disease awareness could be independent of the method used to measure knowledge. [26]

Generally people are more conscious of their health state as they age, as a result, disease knowledge is positively correlated with an increase in age. [26, 41, 65] Still, there is limited evidence on the association between age and the effect of prompting. One cross-sectional study found that the effect of prompting on lung cancer risk factors knowledge was significantly higher amongst participants aged below 40 years compared to those above 40 years [F test (1.1445) =5.18, $p<0.05$)]. [66] On the contrary, another study reported that effects of prompting on the cancer risk factor 'a relative with breast cancer' decreased with increasing age (Wald = 12.8, p=0.002). [26] From these contradicting findings, it is difficult to make any conclusions on the association between age and the prompting effect. More research on the impact of prompting needs to be done, particularly in Sub-Saharan Africa, to provide strong evidence in either direction.

KNOWLEDGE GAP

Much of what is known about the effect of prompting when measuring disease awareness is cited from studies conducted in HIC such as the UK and Canada. [26,48,56,63,66,68]. These studies use open and close ended questions to assess prompted and unprompted knowledge of risk factors and symptoms in a single questionnaire. This has allowed some evaluation on the suitability of each question format to measure knowledge in these settings.

Although various cross sectional studies measuring breast and cervical cancer risk factor and symptom awareness have been conducted in SSA [30-40], there is no consistency in the content (risk factors and symptoms) or question format used in survey questionnaires. Given the evidence from HIC demonstrating that different question formats yield different knowledge scores, it is important to compare the effect of prompted and unprompted questions in the Sub-Saharan context. This evidence will be useful in the development of consistent and context specific questionnaires that accurately measure breast and cervical cancer knowledge in Sub-Saharan Africa.

CONCLUSION

The high breast and cervical cancer incidence and mortality rates in SSA are driven by late presentation of symptoms at healthcare facilities. This late presentation, is partially, a consequence of poor knowledge of disease. Since knowledge is an important precursor to health seeking behavior, this necessitates development of comprehensive public health interventions raising awareness of disease in communities. An initial first step in designing interventions is to first assess current knowledge and identify any gaps. Knowledge can be measured through prompted and unprompted questioning with different outcomes. The use of prompted questioning is advantageous since questions are easy to comprehend and responses are easily quantified during analysis. However, their nature can lead to correct guessing and inflated knowledge scores. Unprompted questioning give the respondent a chance to state their own opinions thus providing more insight on underlying knowledge, but are more difficult to analyze. Given these pros and cons, the use of each method should be highly interrogated

for relevance when measuring breast and cervical cancer risk factors and symptoms knowledge in Sub-Saharan Africa.

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PART C: JOUNAL MANUSCRIPT

MANUSCRIPT COVER PAGE

Comparing women's unprompted and prompted knowledge on breast and cervical cancer risk factors and symptoms in Sub- Saharan Africa

Trish Muzenda[1]

[1]Women's Health Research Unit, School of Public Health and Family Medicine, University of Cape Town, South Africa.

Word count: 3526

Abstract: 394

Tables: 3

Figures: 4

The target journal used to guide formatting of this manuscript in the South African Medical Journal (SAMJ).

In keeping with instructions for this dissertation, the following variations from journal requirements have been made:

1. Figures and tables have been inserted in the text of the manuscript rather than being appended at the end of the article.
2. The article refers to supplementary in the Appendices section of the thesis
3. Co-authors are listed in the Acknowledgements section of the dissertation.
4. The manuscript is in Calibri font with double line spacing.

ABSTRACT

Background: Typically studies using prompted questions to measure breast or cervical cancer risk factors and symptoms report higher knowledge levels compared to those using unprompted questions. Further, there is minimal exploration of the differences between prompted and unprompted knowledge of cancer in the Sub-Saharan Africa (SSA) context.

Objectives: This study sought to measure the differences in breast and cervical cancer risk factors and symptoms knowledge reported through prompted and unprompted questioning in South Africa (SA) and Uganda (UG).

Methods: This was a descriptive cross-sectional study drawing on data collected during validation of an interviewer administered questionnaire (African Woman's Awareness of Cancer - AWACAN) measuring breast and cervical cancer knowledge in SSA. The sample included 139 women recruited from public sector primary health care facilities in two urban districts, Gulu (UG) and Cape Town (SA). Descriptive statistics were used to summarize participant's socio-demographic characteristics and knowledge about breast and cervical cancer. Composite knowledge scores were calculated by adding up the number of correct responses per individual. The Wilcoxon Singed Rank test was used to compare differences between unprompted and prompted knowledge scores. Regression analyses were used to measure the relationship between unprompted and prompted knowledge.

Results: The median age of study participants was 42 years. The majority of women had not completed secondary education (57%) and were unemployed (64%). Unprompted knowledge was considerably lower than prompted knowledge for all breast and cervical cancer risk factors and symptoms. Median scores for unprompted knowledge of breast cancer risk factors (0) and symptoms (1) were significantly lower than for prompted at 6 and 14 respectively. Similarly, the median scores for unprompted knowledge of cervical cancer risk factors (0) and symptoms (1) were lower than prompted knowledge at 6 and 9 respectively. The difference between prompted and unprompted knowledge was least for classical breast and cervical cancer symptoms. For instance, the well-known breast cancer symptom

'lump in the breast' was recalled by 57% and 96% with unprompted and prompted questioning respectively. Unprompted questioning identified additional risk lay beliefs such as, 'itching of the breast'.

Conclusion: Combined use of unprompted and prompted questions provides more insight on breast and cervical cancer knowledge patterns in SSA. The low unprompted knowledge scores reported here demonstrate the need for health education interventions to improve knowledge of established breast and cervical cancer risk factors and whilst addressing any predominant lay beliefs about the disease in SSA.

INTRODUCTION

Breast and cervical cancer are the most prevalent female cancers in Sub-Saharan Africa (SSA). [1] In 2018, cervical cancer was the leading cause of female cancer mortality in 36 SSA countries with age standardized incidence rates ranging from 26.8 to 43.1 cases per 100000. [1,2] Breast cancer incidence ranges from 27.9 to 46.2 cases per 100000. [2] The breast cancer burden in SSA is fuelled by the increasing prevalence of associated risk factors such as poor diet, smoking and aging. [3-5] Cervical cancer incidence is related to the high prevalence of Human Papillomavirus (HPV) infection, immunosuppression (linked to Human Immunodeficiency Virus - HIV) and high parity across SSA. [7] The high mortality rates for both breast and cervical cancer are associated with a shortage of early-detection programmes and insufficient healthcare facilities. Despite the high disease burden in SSA, breast and cervical cancer prevention and control programs are typically not a public health priority [3,6,8] and most countries do not have screening programs for these cancers. [9]. As a result, most cases are diagnosed at a late stage (Stage III and IV) with symptomatic disease. [3-6] This late stage diagnosis is linked to poor prognosis and contributes immensely to the high mortality rates experienced in SSA. Given this context, it is important to improve women's knowledge of breast and cervical cancer such that they may recognize symptoms as soon as they appear and seek prompt medical attention.

Understanding women's knowledge of breast and cervical cancer symptoms and risk factors is critical to inform the development of targeted interventions that promote timely diagnosis. Knowledge may be measured through unprompted (open-ended) and prompted (close-ended) question formats. [10] Unprompted questions assess the individual's ability to remember information stored in memory when given limited or indirect cues in the present. [11-12] Prompted questions measure an individual's ability to make an association between new information (in the present) and similar information stored in memory when given multiple cues. [13-14] Most quantitative studies measuring breast and cervical cancer knowledge [15-25] have utilized prompted rather than unprompted questions. This is because prompted questions are easier to answer and provide quantitative information that can be easily analysed. [26] Only a few cross-sectional studies have measured knowledge using unprompted questions in SSA. [20-21,27-28] Findings from these studies consistently show limited knowledge of established breast and cervical cancer risk factors and symptoms. For example, a study conducted in Togo found that less than 59% of women were aware of any cervical or breast cancer risk factors such as old age and tobacco. [28] Unprompted questions often reveal lay beliefs about cancer risk factors that might not arise in the context of prompted questions such as 'placing mobile phones in ones bra'. [28]

Studies that have compared both methods of questioning often show greater risk factor and symptom knowledge with prompted versus unprompted questions. For instance, a South African cross-sectional study on breast cancer awareness reported that 86% of women had prompted knowledge of 'nipple position chance' as a symptom compared to 13% with unprompted knowledge. [20] Additionally, 59% of respondents recognized 'using hormonal contraceptives' as a breast cancer risk factor when prompted compared to 3% without prompting. A similar study conducted in the United Kingdom (UK) found that participants were four times (OR [95% CI] = 4.24 [3.74–4.81]) as likely to mention 'bleeding/discharge' as a cancer symptom when prompted compared to unprompted. The impact of prompted questioning on recall is associated with factors such as, age, education, information source and familiarity. [13-14,30-32] The lower knowledge scores seen in unprompted versus prompted questions

raises concern about whether prompted questions result in inflated knowledge scores due to guessing of correct answers. [13]

Although breast and cervical cancer knowledge in SSA has been measured, there has been minimal examination on the question formats used to report this knowledge. Growing evidence from high income countries demonstrates differences in knowledge scores reported through unprompted and prompted questions. [13-14,30-32] This warrants exploration of information yielded by using either question format to measure cancer knowledge [20] specifically within the SSA context, so as to identify and address areas of poor knowledge. This information will be useful for breast and cervical cancer awareness interventions that use questionnaires in evaluating their impact. This study sought to measure the differences in breast and cervical cancer knowledge measured through unprompted and prompted questions in Uganda and South Africa.

METHODS

Study design

This descriptive cross-sectional study draws on data collected during psychometric testing of the African Women's Awareness of Cancer (AWACAN) questionnaire (previously known as the Africa Breast and Cervical Cancer Symptom Awareness tool). Responses to questions on socio-demographics and knowledge of risk factors and symptoms were used for this study. Detailed methodology for AWACAN tool development and validation is described elsewhere. [33]

Sample size

The sample size in the parent study was calculated based on a 60-item questionnaire, with 180 participants (including University of Cape Town non-academic staff, community participants and cancer experts), Cronbach alpha cut off of 0.7 and Type I error rate of 5%. [33] The current study uses data collected from community participants (N=139) during the validation process.

Data collection

Women attending public sector primary healthcare facilities in Gulu (UG) and Cape Town (SA) were approached and recruited into the study between August and September 2017 by trained interviewers. The inclusion criteria for participation in the study was as follows; women aged above 18 years, either first or second language English speaker with no previous breast or cervical cancer diagnosis. To begin, trained interviewers approached potential study participants and explained the study process. Thereafter, interested women signed consent forms indicating their willingness to participate in the study. Once consent was given, the interviewer went through the AWACAN questionnaire collecting information on breast and cervical cancer knowledge in face to face interviews. Data was collected until an equal proportion of women aged above and below 50 years to capture knowledge of women at risk for breast and cervical cancer.

Measuring breast and cervical cancer knowledge

Knowledge of risk factors

Knowledge of breast and cervical cancer risk factors was assessed through unprompted and prompted questions. Unprompted questions were asked before prompted questions to reduce recall bias. An example of unprompted question read 'Please could you name as many things as you can think of that could increase a woman's chances of getting breast cancer?' Participants were given an opportunity to freely respond to this question. For data analysis, all free responses to unprompted questions were coded using the deductive coding method. Using this method, all responses were initially reviewed to get a sense of the data. Thereafter, keywords or phrases were generated from established risk factors and symptoms (as outlined in AWACAN). For instance, the keywords 'lump' and 'breast' were used to group symptoms relating to the symptom 'lump in the breast'. Additional groups were generated for responses that were not similar to established risk factors or symptoms. Once all responses had been allocated into groups, a research team with expertise in quantitative and qualitative research reviewed and discussed the allocations until consensus was reached. During data analysis, responses were scored '1' if they mentioned a risk factor corresponding to those listed in the AWACAN

questionnaire to allow for comparison between prompted and unprompted knowledge scores. A '0' score was allocated for each risk factor not mentioned by a participant in unprompted questioning. Subsequently '1' scores were summed up to obtain an unprompted composite knowledge score for each participant.

Prompted questions read 'Could any of the following increase a woman's chances of getting breast cancer?' Thereafter respondents were presented with a list of 13 evidence-based breast cancer risk factors (for cervical cancer, 10 evidence-based cervical cancer risk factors listed). Response options were limited to 'Yes', 'No' and 'I don't know'. For prompted questioning, responses scored '1' for each correct answer 'Yes'. The responses 'No' or 'I don't know' were both scored '0' to indicate lack of knowledge. Composite knowledge scores were calculated as for unprompted with a possible range of 0-13 for breast risk factors and 0-10 for cervical risk factors.

Knowledge of symptoms

Unprompted questions read 'Please would you name as many symptoms or signs of breast cancer as you can think of?' Thereafter participants were given an opportunity to respond freely. Responses to unprompted questions on symptoms were coded as described for risk factors. To allow for comparison between unprompted and prompted knowledge, each recalled symptom (corresponding to those listed in the AWACAN tool) scored '1' if mentioned and '0' if not mentioned. As with risk factor knowledge, unprompted questions were asked before prompted to reduce recall bias.

Prompted questions read, 'Can you tell me if you think the following could be signs of something serious or that something is wrong, such as breast cancer?' Participants were then presented with 15 breast (11 cervical cancer symptoms) and the following response options 'Yes', 'No' and 'I don't know'. Participants scored '1' for each correct answer 'Yes' and '0' if they responded with 'No' or 'I don't know'. Composite symptom knowledge scores were calculate as previously described for risk factor knowledge with a possible range of 0-15 for breast symptoms and 0-11 for cervical symptoms.

Lay beliefs

The AWACAN questionnaire also included common breast and cervical cancer risk factor lay beliefs identified from literature. In total, 6 breast and 1 cervical cancer lay beliefs were presented in the prompted sections. Additional lay beliefs about breast or cervical cancer were grouped and analysed as for responses to unprompted questions.

Data analysis

Data were analysed using STATA version 14.0. Descriptive statistics (mean, median and proportions) were used to characterize socio-demographic characteristics as well as risk factors and symptom knowledge. Univariate logistic regression models were designed to calculate the odds of recalling each risk factor (or symptom) individually with prompted questioning if it was mentioned in unprompted questioning. The Wilcoxon Signed Rank Test was used to compare medians for unprompted and prompted composite knowledge scores for breast and cervical cancer risk factors and symptoms individually. Lastly univariate linear regression models were computed to estimate the linear association between unprompted and prompted composite knowledge scores. P-values of <0.05 denoted statistical significance for all tests and regression models.

Ethical considerations

The study was approved by the Human Research Ethics Committee of the University of Cape Town (Ref. 615/2018), Lacor Hospital Institutional Research Committee (Ref. 027/11/2016) and the Uganda National Council for Science and Technology (Ref. HS60ES).

RESULTS

A total of 139 women from South Africa (72) and Uganda (67) were interviewed. **Table 1** shows the socio-demographic characteristics of study participants. The mean age of respondents was 42 years. Most of the participants had not completed their secondary schooling (57%) and where unemployed (64%).

Table 1: Sociodemographic characteristics of study participants.

Characteristic	Category	Uganda (N=67) n (%)	South Africa (N=72) n (%)	Total (N=139) n (%)
Age (years)	18-49	34 (51%)	43 (60%)	77 (55%)
	50+	33 (49%)	29 (40%)	62 (45%)
Education	No schooling	0 (0%)	1 (1%)	1 (1%)
	Primary education incomplete	9 (13%)	1 (1%)	10 (7%)
	Primary education complete	8 (12%)	7 (10%)	15 (11%)
	Secondary education incomplete	34 (51%)	45 (63%)	79 (57%)
	Secondary education complete	3 (4%)	12 (17%)	15 (11%)
	More than secondary	13 (19%)	6 (8%)	19 (14%)
Employment status	Employed	21 (21%)	29 (40%)	50 (36%)
	Unemployed	46 (67%)	43 (60%)	89 (64%)

Breast cancer knowledge

Knowledge of breast cancer risk factors

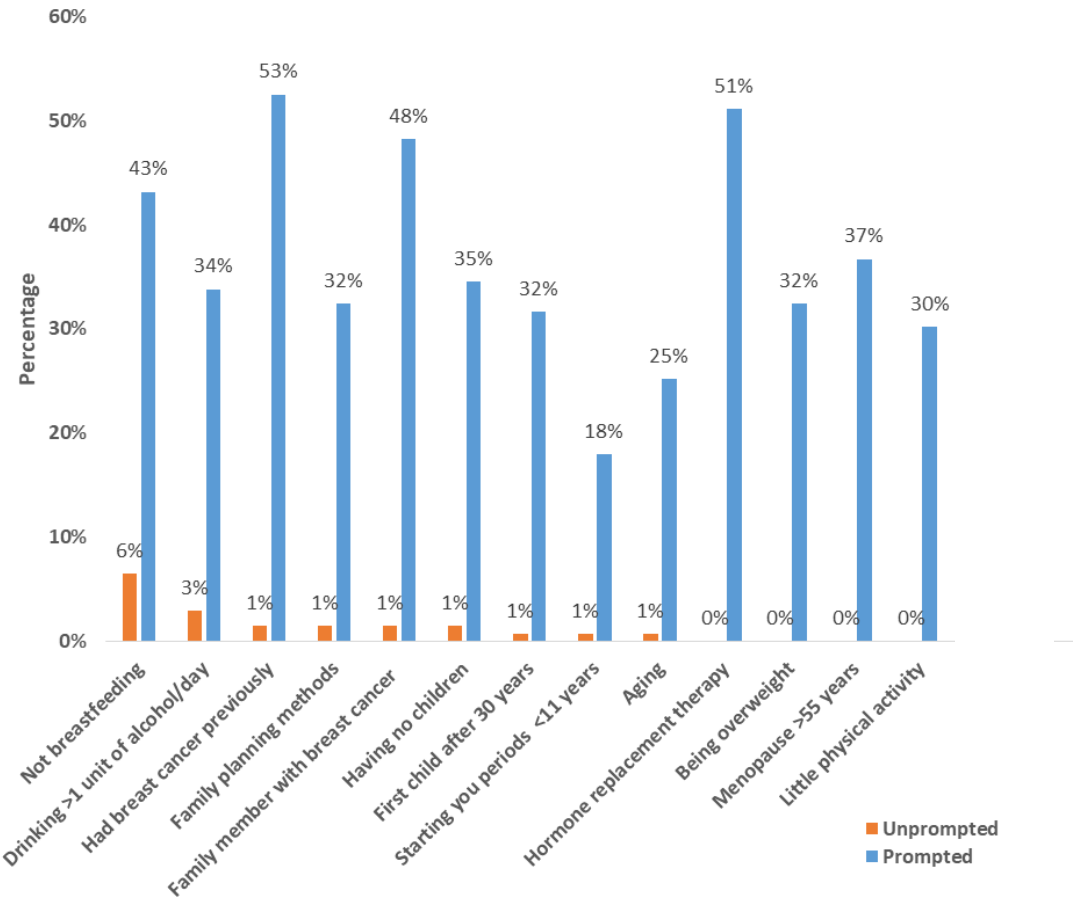

Figure 1: Unprompted and prompted knowledge of established risk factors for breast cancer.

Unprompted knowledge of each breast cancer risk factor was lower than prompted **(Figure 1)**. 'Not breastfeeding' (6%), and drinking less than 1 unit of alcohol per day' (3%) were the most commonly mentioned risk factors with unprompted questioning. Other important risk factors such as 'being overweight' and 'late menopause' were not mentioned by any participants unprompted. Prompted knowledge of risk factors was highest for 'having had breast cancer previously' (53%) and least for 'starting your menstrual periods at age less than 11 years' (18%). Few participants had unprompted knowledge of at least one risk factor (16%) (**Table 2**). The median scores for unprompted and prompted composite knowledge, 0 and 6 respectively, were significantly different (Wilcoxon signed rank test, *p<0.001*) (**Table 2**).

Table 2: Distribution of unprompted and prompted breast cancer composite knowledge scores.

Category	**Unprompted knowledge Median (IQR)**	**Prompted knowledge Median (IQR)**	**Wilcoxon singed rank (p-value)**
Breast cancer risk factors	0 (0-0)	6 (3-13)	p<0.001
Breast cancer symptoms	1 (1-2)	14 (11-15)	p<0.001

Knowledge of breast cancer symptoms

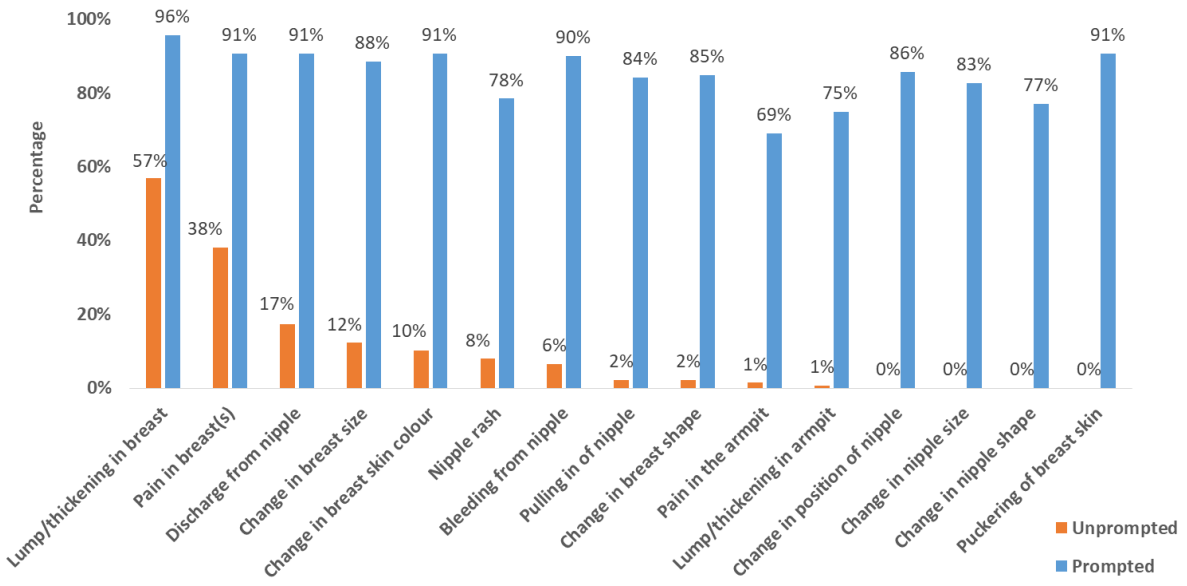

Figure 2: Unprompted and prompted knowledge of breast cancer symptoms.

Unprompted knowledge of symptoms was highest for 'lump/thickening in breast' (57%), 'pain in breast' (38%) and 'discharge from nipple' (17%). Other important symptoms such as 'puckering of breast skin' were not mentioned at all (**Figure 2**). Prompted knowledge of symptoms was high with each risk factor being mentioned by at least 69% of participants. The classical symptom 'lump/thickening in breast' was the most acknowledged symptom for both unprompted (57%) and prompted (96%) questioning. The median unprompted knowledge (1) score was significantly lower than for prompted knowledge (14) (Wilcoxon signed rank test, $p<0.001$) (**Table 2**).

Lay beliefs

Each of the lay beliefs listed in the prompted section of the questionnaire were recalled by less than 15% of participants during unprompted questioning; 'putting money in one's bra' (14%), 'wearing a tight bra' (11%), wearing a bra all the time (4%) and 'putting a mobile phone in one's bra' (4%). In comparison, each of these lay beliefs were endorsed by at least 65% with prompted questioning. Additional risk lay beliefs identified during unprompted questioning were 'unhealthy diet' (9%) and 'sharing clothes' (4%). Additional symptom lay beliefs, 'having a wound/sore/pimple on the breast' (17%), 'itching of the breast' (12%) and 'weight loss' (4%) were also mentioned.

Cervical cancer knowledge

Knowledge of cervical cancer risk factors

As seen in **Figure 3** below, unprompted knowledge of cervical cancer risk factors was highest for factors linked to sexual activity, such as 'many sexual partners' (27%) and 'other STI's' (15%). None of the participants had unprompted knowledge of HPV as a cervical cancer risk factor even though 71% subsequently recalled it when prompted. Prompted knowledge was highest for the risk factors 'many sexual partners' (76%) and 'other STI's' (71%) and 'HPV infection' (71%). The median unprompted (0) and prompted (6) knowledge scores were significantly different (Wilcoxon signed rank test, $p<0.001$) (**Table 3**).

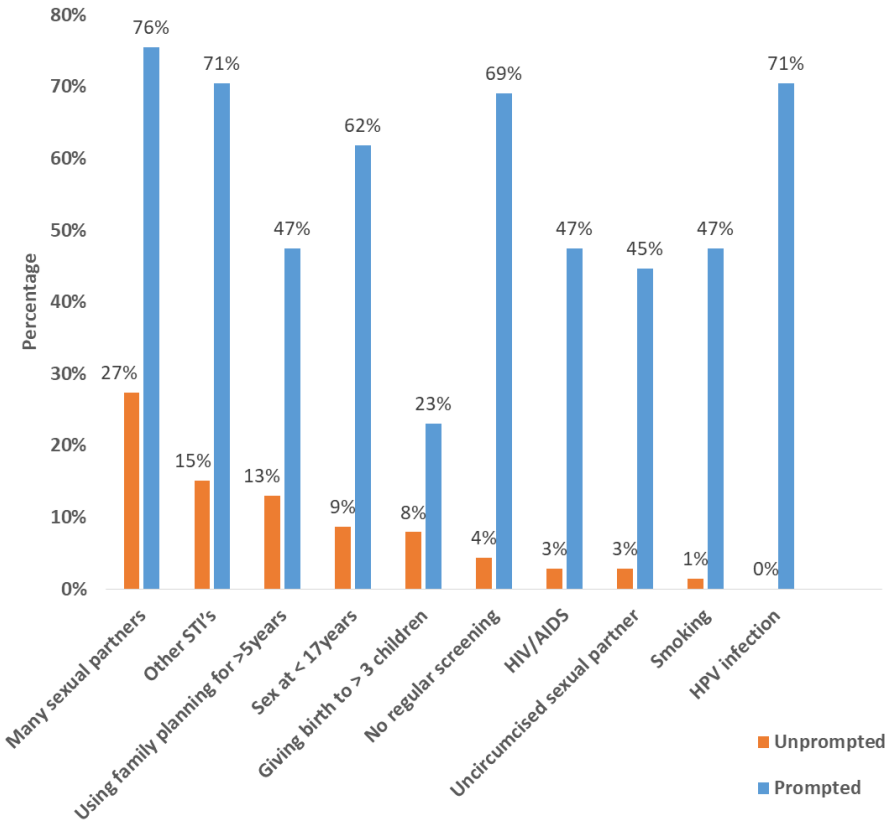

Figure 2: Unprompted and prompted knowledge of cervical cancer risk factors.

Knowledge of cervical cancer symptoms

'Smelly vaginal discharge' (36%) and 'lower abdominal/pelvic pain' (35%) were the most recalled symptoms in unprompted questioning (**Figure 4**). None of the participants recalled 'blood in urine or stool' and 'persistent diarrhoea' as symptoms. Prompted knowledge of cervical cancer symptoms was high with the exception of 'persistent diarrhoea' which was recognized as a symptom by less than 35%. The Wilcoxon Signed Rank test showed a significant difference ($p < 0.001$) between the median knowledge scores for unprompted (1)and prompted (9) questioning (**Table 3**).

Table 3: Distribution of unprompted and prompted cervical cancer composite knowledge scores.

Category	**Unprompted knowledge Median (IQR)**	**Prompted knowledge Median (IQR)**	**Wilcoxon singed rank (p-value)**
Cervical cancer risk factors	0 (0-0)	6 (5-8)	p<0.001
Cervical cancer symptoms	1 (0-2)	9 (7-10)	p<0.001

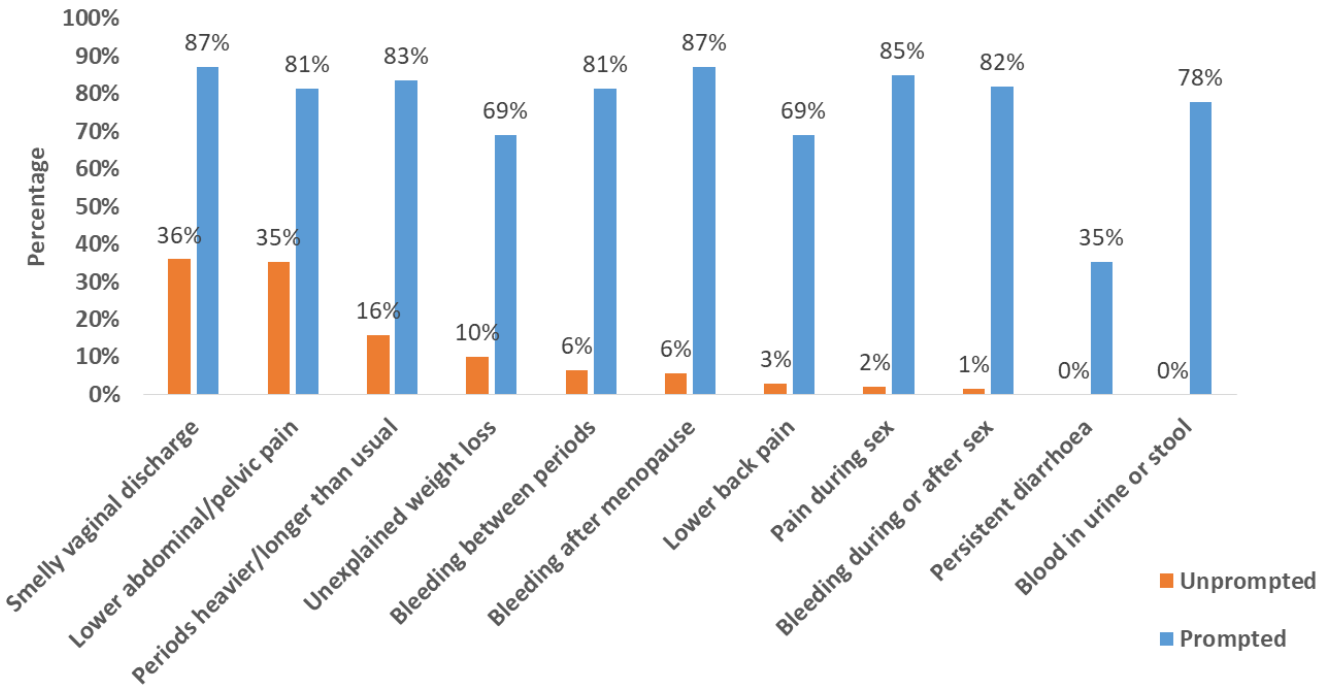

Figure 4: Unprompted and prompted knowledge of cervical cancer symptoms.

Lay beliefs

Additional risk factor lay beliefs identified through unprompted questioning included 'poor personal hygiene' (7%) and 'using condoms for prolonged periods' (5%). Additional symptom lay beliefs uncovered with unprompted questioning included 'sores/wound in the vagina' (17%), 'swelling in the vagina' (9%) and 'itching of the vagina' (20%).

Regression analysis

For the majority of logistic regression models, there was insufficient variability in the explanatory variable (unprompted responses) thereby excluding logistic analysis. All univariate linear regression models (to assess the linear association between unprompted and prompted composite knowledge scores) violated the assumptions for linear regression (i.e. normal distribution and homoscedasticity of residuals) and were thus inefficient in describing the linear association between unprompted and prompted composite knowledge scores (**Appendix 5**).

DISCUSSION

We found that unprompted knowledge of breast and cervical cancer risk factors and symptoms was lower than prompted knowledge. The difference between unprompted and prompted knowledge was least for classical breast (lump in the breast, pain in breast) and cervical (smelly vaginal discharge, lower abdominal pain) cancer symptoms. Unprompted knowledge of cervical cancer risk factors was highest for items related to sexual activity or reproductive factors and least for HPV.

Our findings are in agreement with previous literature showing better knowledge scores reported through use of prompted compared to unprompted questions. [13,17,20,30-32,34-35] Lower scores for unprompted knowledge were expected since participants receive less cues with unprompted compared to prompted questions. Moreover, answering unprompted questions may have required more mental effort and time than was allocated during data collection. [10,14] Conversely, prompted questions provided multiple cues and limited response option thereby making the recall task comparably easier. [14]

In contrast to previous findings reporting poor knowledge of breast or cervical cancer symptoms in SSA, [15-19,20-25] participants in this study demonstrated higher knowledge of symptoms when prompted. The elevated knowledge scores reported here could be indicative of true knowledge as Waller [13] postulates that in real life situations, the appearance of symptoms would ideally prompt an individual to seek medical attention. Nevertheless, it is possible elevated prompted knowledge were partly due to guessing of the correct answer. [13] For example one could easily attribute a drastic change in breast appearance such as 'pulling in of the nipple' to breast cancer because it is unusual.

Additionally, differences in the wording of unprompted and prompted questions in the AWACAN questionnaire could have influenced recall of symptoms. This is because, unprompted questions (Please would you name as many symptoms or signs of breast cancer as you can think of?) made explicit reference to breast or cervical cancer whereas prompted questions (Can you tell me if you think the following could be signs of something serious or that something is wrong, such as breast

cancer) were comparably ambiguous. Consequently, participants may have interpreted the prompted questions as enquiring about knowledge of general disease symptoms not necessarily specific to breast or cervical cancer. To improve on this, careful consideration is needed during the question design process to reduce any biases relating to the way a question is understood.

Both unprompted and prompted knowledge of breast and cervical cancer risk factors was low compared to symptoms, reflecting earlier research. [13,22] The limited knowledge of breast or cervical cancer risk factors presented here is indicative of health education messages not being clear on the association between risk factors and disease. [36] For instance, there was limited knowledge of breast cancer risk factors that are amenable to intervention such as physical exercise and being overweight. Similarly for cervical cancer, there was limited unprompted knowledge on lack of screening and HPV infection as risk factors. The link between risk factors and disease needs to be made explicit in health campaigns, such that women are aware of their risk and may engage in preventative behaviour, such as screening, where possible.

The impact of using prompted questions was least for classic breast and cervical cancer symptoms. For example, the classical breast cancer symptom 'lump in the breast' was recalled by 57% without prompting compared to 96% with prompting. This is similar to other studies demonstrating that the effect of prompting is typically minimal for classical cancer symptoms. [13,20,33] Thus, our findings contribute towards evidence proposing that knowledge of well-known cancer symptoms can be adequately measured using either question format. [13] This improved knowledge of key symptoms is indicative of the emphasis placed by cancer education initiatives on pain and lump related symptoms. [34] Going forth, more effort is required to improve knowledge of the lessor known symptoms as they are equally important in early detection of cancer.

In addition to those listed in AWACAN, other lay beliefs about breast and cervical cancer risk factors and symptoms were revealed through unprompted questioning. For instance, 'itching of the breast' and 'prolonged use of condoms' were identified as breast cancer symptoms and cervical cancer risk

factor respectively. These unprompted responses provided insight on lay beliefs that may be specific to our sample and, as such, not widely documented in literature. Although permissible, these perceptions around breast and cervical cancer need be addressed since incorrect information may hinder prevention and control interventions.

A major strength of our study was that, to our knowledge, this is the first study in SSA exploring the concurrent use of unprompted and prompted questions in assessing breast and cervical cancer knowledge. One limitation of this study is that our sample was small, as such results from this study should be interpreted with caution resulting from potential biases. Additionally, as with all self-reported surveys, participants' knowledge of breast and cervical cancer could not be independently verified to control for social desirability biases.

CONCLUSION

Overall, unprompted knowledge of breast and cervical cancer risk factors and symptoms was lower than prompted. Given that prompted and unprompted questions potentially report on different types of knowledge, where possible, it is worth using both question formats in cancer awareness questionnaires since this provides more insights on cancer knowledge in SSA. Based on our findings, health education interventions need to continuously improve knowledge of established breast and cervical cancer risk factors and symptoms whilst addressing any prevalent lay beliefs.

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PART D: APPENDICES

APPENDIX 1: AFRICAN WOMAN'S AWARENESS OF CANCER (AWACAN) QUESTIONNAIRE

African Woman's Awareness of Cancer - AWACAN Questionnaire

Phase 1 (B). Psychometric testing, community participants

Participant Identification (ID) number: ☐☐☐

Interviewer Code: ☐

Clinic Code: ☐ A = Town Two; B = Kuyasa; C = Nolungile; D = Zakhele

Date of Interview: Day ☐☐ Month ☐☐ Year ☐☐

ELIGIBILITY CHECK

1. **Is the client female?**
   1 = Yes
   2 = No → Stop
2. **Is the participant 18 years of age or older?**
   1 = Yes
   2 = No → Stop
3. **Does the participant understand and speak English?**
   1 = Yes
   2 = No → Stop
4. **Has the participant been diagnosed with breast or cervical cancer?**
   1 = Yes → Stop
   2 = No → Proceed with questionnaire

AFRICAN WOMAN'S AWARENESS OF CANCER (AWACAN) QUESTIONNAIRE

English

<Version 1.7 Revision 5>

August 18th 2017

SECTION 1: SOCIO-DEMOGRAPHIC QUESTIONS

READ: "Thank you for agreeing to talk with me. To start, I am going to ask you some questions about yourself."

Interviewer note: The 'did not answer' option must not be read out as an option to participants.

READ ALOUD EACH QUESTION

No.	Questions and filters	Response
101.	How old are you? *Interviewer note: If the participant does not know their age, ask for their Date of Birth, calculate their age and write it down. If the participant does not know their age or date of birth or does not want to reveal their age circle "did not answer"*	_____ years
		Did not answer
102.	What is your current relationship status? **READ OUT ALL THE OPTIONS AND SELECT ONE ANSWER**	Married
		Living together with a partner
		Single
		Separated/Divorced
		Widowed
		Did not answer
103.	What is your highest level of education? *Interviewer note: use school grade and standard guide to assist you* **CIRCLE ONLY ONE RESPONSE**	No schooling
		Primary incomplete
		Primary complete
		Secondary incomplete
		Secondary complete
		More than secondary
		Did not answer
104.	What is the main language spoken at home? **CIRCLE ONLY ONE RESPONSE**	**South Africa**
		Xhosa
		Afrikaans
		English
		Other (please specify)……
		Did not answer
		Uganda
		Luo/Acholi
		English
		Swahili
		Other (please specify)…….
		Did not answer

105.	Do you have a job for which you get paid or from which you earn money? **CIRCLE ONLY ONE RESPONSE**	Yes
		No
		Did not answer
106.	In what type of dwelling or type of housing do you live? **READ OUT RESPONSES AND CIRCLE ONLY ONE RESPONSE**	Brick house/apartment
		Informal dwelling/shack (e.g. in an informal or squatter settlement)
		Traditional dwelling/hut/structure made of traditional materials
		Other (please specify)……
		Did not answer
107.	Can you tell me whether you have any of the following where you live: **CIRCLE ONLY ONE RESPONSE PER QUESTION**	
	a) Do you have electricity?	Yes
		No
		Did not answer
	b) Do you have tap water in your house, compound, or property?	Yes
		No
		Did not answer
	c) Do you have a toilet in your house, compound, or property?	Yes
		No
		Did not answer
	d) Do you or does anyone living with you have a radio?	Yes
		No
		Did not answer
	e) Do you or does anyone living with you have a television?	Yes
		No
		Did not answer
	f) Do you or does anyone living with you have internet access on a computer, a laptop or a mobile phone?	Yes
		No
		Did not answer

SECTION 2: INTRODUCTION – BREAST CANCER SYMPTOM AWARENESS MEASURE

READ: "I would now like to ask you some questions about breast cancer."

READ ALOUD EACH QUESTION

No.	Questions and filters	Response
201.	Have you ever heard of breast cancer? **IF "NO" SKIP TO 402 = KNOWLEDGE OF SYMPTOMS**	Yes
		No
202.	Do you know of any family members, friends or neighbours who have/had breast cancer?	Yes
		No
		Don't Know

SECTION 3: KNOWLEDGE OF RISK FACTORS

The following is an open question seeking to find out how much women know about breast cancer risk factors.

301. READ: "Please could you name as many things as you can think of that could increase a woman's chances of getting breast cancer?"

WRITE DOWN ALL THE RISK FACTORS THE WOMAN GIVES IN THE SPACE PROVIDED BELOW (ONE RISK FACTOR PER LINE). WRITE DOWN CLEARLY AND EXACTLY AS THEY SAY IT.

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302. READ: "Could any of the following increase a woman's chances of getting breast cancer?"

READ ALOUD EACH QUESTION AND CIRCLE ONLY ONE RESPONSE PER QUESTION.

No.	Questions and filters	Response
a)	Having had breast cancer previously	Yes
		No
		Don't know
b)	Drinking more than 1 bottle of beer or 1 glass of other types of alcohol per day	Yes
		No
		Don't know
c)	Using hormone replacement therapy *[Explanation]: When some women stop getting their periods, they sometimes get symptoms such as hot flushes because their hormone levels are low. The medication they may be given for such symptoms is called hormone replacement therapy*	Yes
		No
		Don't know
d)	Using family planning methods (e.g. the pill, injectable contraceptives and implants)	Yes
		No
		Don't know
e)	Being overweight	Yes
		No
		Don't know
f)	Having a family member with breast cancer	Yes
		No
		Don't know
g)	Having the first child after the age of 30 years	Yes
		No
		Don't know
h)	Having no children at all	Yes
		No
		Don't know
i)	Starting your periods **early**, that is before the age of 11 years	Yes
		No
		Don't know
j)	Having menopause **late**, that is after the age of 55 years *[Explanation]: This is when a woman's period stops permanently*	Yes
		No
		Don't know
k)	Doing little physical activity or manual labour	Yes

		No
		Don't know
l)	Aging/growing old	Yes
		No
		Don't know
m)	Not breastfeeding	Yes
		No
		Don't know
n)	Stress	Yes
		No
		Don't know
o)	Being exposed to dirty air or water	Yes
		No
		Don't know
p)	Wearing a tight bra	Yes
		No
		Don't know
q)	Wearing a bra all the time	Yes
		No
		Don't know
r)	Putting money in one's bra	Yes
		No
		Don't know
s)	Putting a mobile phone in one's bra	Yes
		No
		Don't know
t)	Being bewitched/witchcraft	Yes
		No
		Don't know

SECTION 4: KNOWLEDGE OF SYMPTOMS

The following is an open question seeking to find out how many symptoms or signs of breast cancer women know.

401. READ: "Please would you name as many symptoms or signs of breast cancer as you can think of?"

WRITE DOWN ALL THE SYMPTOMS OR SIGNS THE WOMAN GIVES IN THE SPACE PROVIDED BELOW (ONE SYMPTOMS OR SIGNS PER LINE). WRITE DOWN CLEARLY AND EXACTLY AS THEY SAY IT.

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402. READ: "Can you tell me if you think the following could be signs of something serious or that something is wrong, such as breast cancer?"

READ ALOUD EACH QUESTION AND CIRCLE ONLY ONE RESPONSE PER QUESTION.

No.	Questions and filters	Response
a)	A change in the position of the nipple *[Explanation]: such as pointing up or down or in a different direction to normal* **SHOW PICTURE TO ILLUSTRATE**	Yes No Don't know
b)	Pulling in of the nipple *[Explanation]: Where the nipple no longer points outwards but into the breast* **SHOW PICTURE TO ILLUSTRATE**	Yes No Don't know
c)	A change in the size of the nipple, not when pregnant or breast feeding	Yes No Don't know
d)	A change in the shape of the nipple, not when pregnant or breast feeding	Yes No Don't know
e)	Nipple rash	Yes No Don't know
f)	Discharge from the nipple, not when pregnant or breast feeding	Yes No Don't know
g)	Bleeding from the nipple	Yes No Don't know
h)	Pain in one or both breasts	Yes No Don't know
i)	A lump or thickening in the breast	Yes No Don't know
j)		Yes

	A change in colour of the breast skin, not when pregnant or breastfeeding	No
		Don't know
k)	Puckering or dimpling of the breast skin *[Explanation]: like a dent or orange peel appearance of the skin* **SHOW PICTURE TO ILLUSTRATE**	Yes
		No
		Don't know
l)	A change in the size of the breast, not when pregnant or breast feeding	Yes
		No
		Don't know
m)	A change in the shape of the breast, not when pregnant or breastfeeding	Yes
		No
		Don't know
n)	A lump or thickening under the armpit/under arm	Yes
		No
		Don't know
o)	Pain in the armpit/under arm	Yes
		No
		Don't know

SECTION 5: HELP-SEEKING BEHAVIOUR

READ: "Now, I would like to ask you what you would do if you noticed a breast change such as a lump, pain in the breast, bleeding from the nipple or a change in position of the nipple"

These questions aim to find out where women would initially seek help after discovering a breast change.

READ ALOUD EACH QUESTION.

No.	Questions and filters	Response
501.	a) If you noticed a change in your breast or breasts, would you ignore it?	Yes
		No
		Don't know
	b) If you noticed a change in your breast or breasts, would you hope it will go away?	Yes
		No
		Don't know
	c) If you noticed a change in your breast or breasts, would you try self-medication, for example get some ointment to apply from the local supermarket?	Yes
		No
		Don't know
	d) If you noticed a change in your breast or breasts, would you tell someone close to you?	Yes
		No
		Don't know
	e) If you noticed a change in your breast or breasts, would you pray for healing?	Yes
		No
		Don't know
	f) If you noticed a change in your breast or breasts, would you visit a traditional healer?	Yes
		No
		Don't know
	g) If you noticed a change in your breast or breasts, would you go straight to the nearest healthcare facility, such as a pharmacy or clinic or health centre or hospital? *Interviewer note: It is any one of the given healthcare provider options*	Yes
		No
		Don't know
	h) If you noticed a change in your breast or breasts, is there anything else you would do? (please specify): …….. …….. …….. …….. ……..	
502.		Immediately

	ONLY FOR THOSE WHO SAID 'YES' IN 501F i.e. 'VISIT A TRADITIONAL HEALTH PRACTITIONER' If you noticed a change in your breast or breasts, how soon would you visit a traditional healer? **READ ALOUD EACH RESPONSE AND CIRCLE ONLY ONE**	< 1 week
		≥1 week < 1 month
		≥ 1 month < 3 months
		≥ 3 months < 1 year
		≥ 1 year
503.	**FOR ALL WOMEN** If you noticed a change in your breast or breasts, how soon would you visit the pharmacy or clinic or health centre or hospital? **READ ALOUD EACH RESPONSE AND CIRCLE ONLY ONE** *Interviewer note: It is any one of the given healthcare provider options*	Never
		Immediately
		< 1 week
		≥ 1 week < 1 month
		≥ 1 month < 3 months
		≥ 3 months < 1 year
		≥ 1 year

SECTION 6: CONFIDENCE SKILLS AND BEHAVIOR IN RELATION TO BREAST CHANGES

These questions aim to measure confidence, skills and behaviour to detect breast changes and act upon detecting such changes.

READ ALOUD EACH QUESTION

No.	Questions and filters	Response
601.	Do you ever check your breasts?	Yes
		No
602.	Are you confident that you would notice a change in your breasts?	Yes
		No
		Don't know
603.	Have you ever been to see a nurse or clinical officer or doctor about a change you have noticed in your breasts? **READ ALOUD OPTIONS AND CIRCLE ONLY ONE** *Interviewer note: It is any one of the given healthcare provider options*	Yes
		No
		Never noticed a change in my breasts
604.	Have you ever been to see a traditional healer about a change you have noticed in your breasts? **READ ALOUD OPTIONS AND CIRCLE ONLY ONE**	Yes
		No
		Never noticed a change in my breasts

SECTION 7: INTRODUCTION – CERVICAL CANCER AWARENESS MEASURE

READ: "I would now like to ask you some questions about cervical cancer."

READ ALOUD EACH QUESTION

No.	Questions and filters	Response
701.	Have you ever heard of cervical cancer/cancer of the mouth of the womb? **IF "NO" SKIP TO SECTION 902 = KNOWLEDGE OF SYMPTOMS**	Yes
		No
702.	Do you know of any family members, friends or neighbours who have/had cervical cancer?	Yes
		No

SECTION 8: KNOWLEDGE OF RISK FACTORS

The following is an open question to find out how much women know about cervical cancer risk factors.

801. READ: "Please could you name as many things as you can think of that could increase a woman's chances of getting cervical cancer?"

WRITE DOWN ALL THE RISK FACTORS THE WOMAN GIVES IN THE SPACE PROVIDED BELOW (ONE RISK FACTOR PER LINE). WRITE DOWN CLEARLY AND EXACTLY AS THEY SAY IT.

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802. READ: "Could any of the following increase a woman's chances of getting cervical cancer?"

READ ALOUD EACH QUESTION AND CIRCLE ONLY ONE RESPONSE PER QUESTION.

No.	Questions and filters	Response
a)	Getting a sexually transmitted infection called the Human Papillomavirus (HPV)	Yes
		No
		Don't know
b)	HIV/AIDS	Yes
		No
		Don't know
c)	Being infected with other sexually transmitted diseases (other than HIV or Human Papillomavirus)	Yes
		No
		Don't know
d)	Using birth control pills/family planning for more than 5 years	Yes
		No
		Don't know
e)	Smoking any cigarettes at all	Yes
		No
		Don't know
f)	Having a sexual partner who is not circumcised	Yes
		No
		Don't know
g)	Having sex at a young age (17 years or younger)	Yes
		No
		Don't know
h)	Giving birth to three or more children	Yes
		No
		Don't know
i)	Having many sexual partners	Yes
		No
		Don't know
j)	Not going for regular screening/testing for cervical cancer	Yes
		No
		Don't know
k)	Being bewitched/witchcraft	Yes
		No
		Don't know

SECTION 9: KNOWLEDGE OF SYMPTOMS

The following question is an open question seeking to find out how many symptoms or signs of cervical cancer women know.

901. READ: "Please would you name as many symptoms or signs of cervical cancer as you can think of?"

WRITE DOWN ALL THE SYMPTOMS OR SIGNS THE WOMAN GIVES IN THE SPACE PROVIDED BELOW (ONE SYMPTOM OR SIGN PER LINE)

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902. READ: "Can you tell me if you think the following could be signs of something serious or that something is wrong such as cervical cancer?"
READ ALOUD EACH QUESTION AND CIRCLE ONLY ONE RESPONSE PER QUESTION.

No.	Questions and filters	Response
a)	Vaginal bleeding between menstrual periods	Yes
		No
		Don't know

b)	Persistent lower back pain	Yes
		No
		Don't know
c)	A persistent smelly vaginal discharge	Yes
		No
		Don't know
d)	Discomfort or pain during sex	Yes
		No
		Don't know
e)	Menstrual periods that are longer or heavier than usual	Yes
		No
		Don't know
f)	Persistent diarrhoea	Yes
		No
		Don't know
g)	Vaginal bleeding after menopause	Yes
	[Explanation]: Menopause is when a woman's periods have stopped permanently	No
		Don't know
h)	Persistent lower abdominal/pelvic pain	Yes
		No
		Don't know
i)	Vaginal bleeding during or after sex	Yes
		No
		Don't know
j)	Blood in urine or stool (faeces)	Yes
		No
	[Explanation]: Blood in pee/wee or poo	Don't know
k)	Unexplained weight loss	Yes
		No
		Don't know

SECTION 10: HELP-SEEKING BEHAVIOUR

READ: "Now, I would like to ask you what you would do if you had any symptom coming from the mouth of your womb or cervix such as bleeding between periods, bleeding after sex or after menopause or pain or change in vaginal discharge"

These questions aim to find out where women would initially seek help after discovering a change in their cervix/womb.

READ ALOUD EACH QUESTION.

No.	Questions and filters	Response
1001.		
	a) If you had a symptom coming from your cervix or mouth of your womb, would you ignore it?	Yes
		No
		Don't know
	b) If you had a symptom coming from your cervix or mouth of your womb, would you hope it will go away?	Yes
		No
		Don't know
	c) If you had a symptom coming from your cervix or mouth of your womb, would you try self-medication, for example get some ointment to apply from the local supermarket?	Yes
		No
		Don't know
	d) If you had a symptom coming from your cervix or mouth of your womb, would you tell someone close to you?	Yes
		No
		Don't know
	e) If you had a symptom coming from your cervix or mouth of your womb, would you pray for healing?	Yes
		No
		Don't know
	f) If you had a symptom coming from your cervix or mouth of your womb, would you visit a traditional healer?	Yes
		No
		Don't know
	g) If you had a symptom coming from your cervix or mouth of your womb, would you go straight to the nearest healthcare facility, such as a pharmacy or clinic or health centre or hospital? *Interviewer note: It is any one of the given healthcare provider options*	Yes
		No
		Don't know
	h) If you had a symptom coming from your cervix or mouth of your womb, is there anything else you would do? (please specify): …….. …….. …….. …….. ……..	
1002.	**ONLY FOR THOSE WHO SAID 'YES' IN 1001F i.e. 'VISIT A TRADITIONAL HEALER'** If you had a symptom coming from your cervix or womb, how soon would you visit a traditional healer? **READ ALOUD EACH RESPONSE AND CIRCLE ONLY ONE**	Immediately
		< 1 week
		≥1 week < 1 month
		≥ 1 month < 3 months
		≥ 3 months < 1 year
		≥ 1 year

1003.	**FOR ALL WOMEN** If you had a symptom coming from your cervix or womb, how soon would you visit the pharmacy/clinic/health centre/hospital? **READ ALOUD EACH RESPONSE AND CIRCLE ONLY ONE** *Interviewer note: It is any one of the given healthcare provider options*	Never
		Immediately
		< 1 week
		≥ 1 week < 1 month
		≥ 1 month < 3 months
		≥ 3 months < 1 year
		≥ 1 year

SECTION 11: CONFIDENCE SKILLS AND BEHAVIOR IN RELATION TO A CERVICAL CANCER SIGN/SYMPTOM

These questions aim to measure the confidence, skills and behaviour to detect signs/symptoms of cervical cancer and to act upon detecting such signs/symptoms.

READ ALOUD EACH QUESTION

No.	Questions and filters	Response
1101.	Are you confident that you would notice a symptom that could be cervical cancer? **CIRCLE ONLY ONE**	Yes No Don't know
1102.	Have you ever been to see a nurse or clinical officer or doctor about a symptom that made you think something was wrong, like a symptom of cervical cancer? **READ THE OPTIONS AND CIRCLE ONLY ONE** *Interviewer note: It is any one of the given healthcare provider options*	Yes No Not noticed any symptoms or signs
1103.	Have you ever been to see a traditional healer about a symptom that made you think something was wrong, like a symptom of cervical cancer? **READ THE OPTIONS AND CIRCLE ONLY ONE**	Yes No Not noticed any symptoms or signs

SECTION 12: BARRIERS TO SEEKING MEDICAL HELP [FOR BOTH BREAST AND CERVICAL CANCER]

READ: "The next question is about seeking medical help for a symptom or sign of **breast or cervical cancer.** Sometimes people put off going for medical help even when they have noticed a sign or symptom which they think might be serious."

1201. "Would any of the following reasons make it difficult for you to see the nurse or clinical officer or doctor if you noticed a symptom or sign which you think may be serious, for example a change in your breast or a change in the mouth of your womb or cervix that could be cancer?"

Interviewer note: It is any one of the given healthcare provider options

READ ALOUD EACH QUESTION AND CIRCLE ONLY ONE RESPONSE PER QUESTION

No.	Questions and filters	Response
a)	Would feeling too embarrassed make it difficult for you to go and see the nurse/clinical officer/doctor?	Yes
		No
		Don't know
b)	Would feeling too scared make it difficult for you to go and see the nurse/clinical officer/doctor?	Yes
		No
		Don't know
c)	Would feeling worried about wasting the nurse's/clinical officer's/doctor's time make it difficult for you to see them?	Yes
		No
		Don't know
d)	Would feeling worried about what they might find wrong make it difficult for you to see them?	Yes
		No
		Don't know
e)	Would feeling worried about what tests they might want to do make it difficult for you to see them?	Yes
		No
		Don't know
f)	Would being too busy to make time to go to the nurse/clinical officer/doctor make it difficult for you to see them?	Yes
		No
		Don't know
g)	Would having no money for transport or clinic/health centre charges make it difficult for you to see them?	Yes
		No
		Don't know
h)	Would taking too long to be seen at the clinic/health centre make it difficult for you to see them?	Yes
		No
		Don't know
i)		Yes

	Would having too many other things to worry about make it difficult for you to see them?	No
		Don't know
j)	Would not feeling confident to talk about your symptom(s) with the nurse/clinical officer/doctor make it difficult for you to see them?	Yes
		No
		Don't know
k)	Would having had a bad experience in the clinic/health centre in the past make it difficult for you to see them?	Yes
		No
		Don't know
l)	Would feeling worried that your nurse/clinical officer/doctor may not take my symptoms seriously make it difficult for you to see them?	Yes
		No
		Don't know
m)	Would talking to the person at the reception/front desk about your symptoms make it difficult for you to see them?	Yes
		No
		Don't know
n)	Would the nurse/clinical officer/doctor not understanding your language make it difficult for you to see them?	Yes
		No
		Don't know
o)	Would the nurse/clinical officer/doctor not understanding your culture make it difficult for you to see them?	Yes
		No
		Don't know
p)	Would your husband or partner not allowing you to go, make it difficult for you to see them? *Interviewer note: If single or widowed ask:* If you had a husband or partner not allowing you to go, would this make it difficult for you to see the nurse/clinical officer/doctor?	Yes
		No
		Don't know
q)	Would being healthy, so not expecting to get cancer, make it difficult for you to see them?	Yes
		No
		Don't know
r)	Would thinking "If I have a serious disease like cancer, there is no use for the nurse/clinical officer/doctor and I will die anyway" make it difficult for you to see them?	Yes
		No
		Don't know
s)	Is there anything else that would make it difficult for you to see a nurse or clinical officer or doctor? (Please specify …….	

READ: "We have come to the end of this interview. Thank you for your time. The information you have shared has been very helpful."

FOR OFFICIAL USE ONLY

Checked by Field Coordinator

Name:

Signature:

Date:

Checked by Project Manager

Name:

Signature:

Date:

APPENDIX 2: LETTERS OF ETHICS APPROVAL FROM UCT HUMAN RESEARCH ETHICS COMMITTEE, UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

26 September 2018

HREC REF: 615/2018

Prof Jennifer Moodley
Public Health & Family Medicine
Falmouth Building

Dear Prof Moodley

PROJECT TITLE: COMPARING PROMPTED AND UNPROMPTED RECALL OF WOMEN'S KNOWLEDGE ON BREAST AND CERVICAL CANCER RISK FACTORS AND SYMPTOMS (Masters Candidate - Ms T Muzenda) Sub-study linked to 544/2016

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 September 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Trish Muzenda will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

From: Research Management - UNCST <research@uncst.go.ug>
Reply-To: Jennifer Moodley <jennifer.moodley@uct.ac.za>
Date: Friday, 30 June 2017 at 10:57 AM
To: Jennifer Moodley <jennifer.moodley@uct.ac.za>
Subject: Study Approval - (HS60ES)

Uganda National Council for Science and Te

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS60ES 2017-06-30

Dear Jennifer Moodley,

I am pleased to inform you that on **30/06/2017**, the Uganda National Council for Science and Technology (UNCST) approved your study titled, **Improving timely diagnosis of symptomatic breast and cervical cancer in Sub-Saharan Africa**. The Approval is valid for the period of **30/06/2017** to **30/06/2020**.

Your study reference number is **HS60ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above study.

Please, note that as Principal Investigator, you are responsible for:

1. Keeping all co-investigators informed about the status of the study.
2. Submitting any changes, amendments, and addenda to the study protocol or the consent form, where applicable, to the designated local Research Ethics Committee (REC) or Lead Agency, where applicable, for re-review and approval prior to the activation of the changes.
3. Notifying UNCST about the REC or lead agency approved changes, where applicable, within five working days.
4. For clinical trials, reporting all serious adverse events promptly to the designated local REC for review with copies to the National Drug Authority.
5. Promptly reporting any unanticipated problems involving risks to study subjects/participants to the UNCST.
6. Providing any new information which could change the risk/benefit ratio of the study to the UNCST for review.
7. Submitting annual progress reports electronically to UNCST. Failure to do so may result in termination of the research project.

Please, note that this approval includes all study related tools submitted as part of the application.

Yours sincerely,

Hellen N. Opolot
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

APPENDIX 3: PARTICIPANT INFORMATION AND CONSENT FORM

Information and informed consent

Development and validation of the African Woman's Awareness of Cancer (AWACAN) tool

Phase 1 (B). Psychometric testing, community participants

Principal investigator: **Assoc. Professor Jennifer Moodley**
Director Cancer Research Initiative
Faculty of Health Sciences
University of Cape Town

Co-principal investigator: **Dr Fiona Walter**
Clinical Principal Researcher in
Primary Care Cancer Research
Department of Public Health & Primary Care
University of Cambridge

Information

Introduction

Please let me introduce myself, my name is ….(name of interviewer) and I work at the University of Cape Town/ Makerere University. I am part of a research team from the Universities of Cape Town, Cambridge, King's College London and Makerere and the South African Medical Research Council and we are talking to women from South Africa and Uganda to understand their views on breast and cervical cancer (also known as cancer of the womb) symptoms.

Breast and cervical cancer are the most common cancers found in women. This study will help us understand women's awareness of and beliefs about breast and cervical cancer symptoms and how they might seek help for these symptoms. This information will be useful in designing future interventions to improve early detection of breast and cervical cancer.

We have developed a set of questions that we want to ask women in the community about breast and cervical cancer. We first need to check whether the questions that we have developed are relevant and reliable. I would like to invite you to take part in a small study where I will ask you a set of questions and write down you responses. The response we receive from you will be used to revise and finalize the set of questions. If there is anything that you do not understand at any time, I will be happy to explain.

Please note, your participation in this study is entirely voluntary and you are free to stop participating at any time.

If you decide to take part in this study:

- The interview will last about 30 minutes
- I will ask you to sign a consent form
- I will ask you some questions and write down your responses
- The information collected will be stored in a secure database in South Africa and only the research team will have access to the data
- Your name will not be recorded for this study
- You can choose to skip any questions or stop at any stage

Your participation in this study will help us understand women's beliefs and awareness about breast and cervical cancer symptoms and how they seek help for these symptoms. Your participation will not directly benefit you now, however it will assist us in designing interventions to improve early detection of these cancers and could benefit other women in the future.

If you decide not to take part in this research project:

The quality of the medical care you receive now, or in the future, will not be affected in any way.

Let me explain the benefits of participating in this study

You will not benefit directly from the study now, but by taking part you will be helping us to design better ways to inform people about these cancers. This could be of benefit to women and their families in the future.

Let me explain possible risks of participating in this study

There are no direct risks involved in participating in this study. There is a slight risk that you may share some personal or private information by chance or that you may feel uncomfortable about talking about certain things. However, we do not wish this to happen, and you may decide to not answer any question or not take part in any part of the interview if you feel the question(s) are personal or if talking about them makes you uncomfortable.

Confidentiality

The information that we collect from this research project will be kept confidential. We will not record your name for this study, instead we will assign you a study number. Your name will not be used in any of the results from this study.

Right to refuse or withdraw

You do not have to take part in this study if you do not wish to do so, and not taking part will not affect your treatment at the health facility in any way. You will still have all the benefits that you would otherwise have at this health facility. You may stop taking part in the interview at any time that you wish without losing any of your rights as a patient.

Additional information

If you have any symptoms or concerns about your health, we will give you a referral note to your nearest public health facility. If you have any questions or if anything we discussed is unclear, please let me know and I will be happy to explain now or at any time during the study.

If you need more information about his study, you may contact:

Professor Jennifer Moodley
Cancer Research Initiative
University of Cape Town
Tel: +27(0) 21 650 5489
Email jennifer.moodley@uct.ac.za

Dr Amos Deogratius Mwaka
Department of Medicine
Makerere University
Tel: +256-772-569996
E-mail: mwakaad@yahoo.com / mgratius@gmail.com

If you have any questions regarding your rights as a study participant, please contact:
South Africa
Professor M Blockman
Chairperson, Human Research Ethics Committee
University of Cape Town
Tel: +27 (0)21 406 6496

Uganda
Professor Ocama Ponsiano
Makerere University School of Medicine Research Ethics Committee
Email: rresearch9@gmail.com
Telephone number: +256 414 -533541

This research project has been approved by the Health Research Ethics Committee (HREC) at The University of Cape Town and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki (2013) and the South African Guidelines for Good Clinical Practice (2006).

Research Team

Lead South African investigator	Prof Jennifer Moodley Director Cancer Research University of Cape Town (UCT)
Lead UK investigator	Dr Fiona Walter Department of Public Health & Primary Care University of Cambridge, UK
Lead Ugandan investigator	Dr Amos Deogratius Mwaka Department of Medicine Makerere University

South African co-investigators
Prof Lynette Denny, Dept. of Obstetrics and Gynaecology, UCT
Dr Tolullah Oni, School of Public Health and Family Medicine, UCT
Ms Ntuthu Somdyala , SA Medical Research Council
Dr Lydia Cairncross, Dept. of Surgery, UCT

UK co-investigator
Dr Suzanne Scott, Division of Population and Patient Heath, King's College London

Ugandan co-investigator
Prof Henry Wabinga, Kampala Cancer Registry, Makerere University

Consent

I have read and I understand the information provided for participation in the study entitled: Development and validation of the African Woman's Awareness of Cancer (AWACAN) tool.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had time to consider whether I will take part.

I understand that taking part in this study is confidential and that no material which could identify me will be used in any reports on this study.

Declaration by participant

I_____ (full name and surname) hereby consent to participating in this study entitled: Development and validation of the African Woman's Awareness of Cancer (AWACAN) tool.

Signature _____ Date _____

Declaration by investigator

Project explained by _____ (First name and surname)
Signature _____ Date_____

<u>If the participant is unable to read and fully understand the informed consent document on his or her own:</u>

Declaration by witness

I_____ (full name and surname of witness) hereby acknowledge that the informed consent has been explained to the participant and he/she understands the information provided.

APPENDIX 4: AUTHOR INSTRUCTIONS FOR THE SOUTH AFRICAN MEDICAL JOURNAL

South African Medical Journal Submissions

AUTHORSHIP

Named authors must consent to publication. Authorship should be based on: (*i*) substantial contribution to conceptualisation, design, analysis and interpretation of data; (*ii*) drafting or critical revision of important scientific content; or (*iii*) approval of the version to be published. These conditions must all be met (uniform requirements for manuscripts submitted to biomedical journals; refer to www.icmje.org)

CONFLICTS OF INTEREST

We require that both authors and reviewers declare all sources of support for their research, any personal or financial relationships (including honoraria, speaking fees, gifts received, etc.) with relevant individuals or organisations connected to the topic of the paper, and any association with a product or subject that may constitute a real, perceived or potential conflict of interest.

RESEARCH ETHICS COMMITTEE APPROVAL

Authors must provide evidence of Research Ethics Committee approval of the research where relevant. Ensure the correct, full ethics committee name and reference number is included in the manuscript.

PROTECTION OF RIGHTS TO PRIVACY

Information that would enable identification of individual patients should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) has given informed written consent for publication and

distribution. We further recommend that the published article is disseminated not only to the involved researchers but also to the patients/participants from whom the data was drawn.

COPYRIGHT NOTICE

Material submitted for publication in the *SAMJ* is accepted provided it has not been published or submitted for publication elsewhere. The *SAMJ* does not hold itself responsible for statements made by the authors.

ETHNIC/RACE CLASSIFICATION

If you choose to use a research design that involves classification of participants based on race or ethnicity, or discuss issues with reference to such classifications, please ensure that you include a detailed rationale for doing so, ensure that the categories you describe are carefully defined, and that socioeconomic, cultural and lifestyle variables that may underlie perceived racial disparities are appropriately controlled for.

MANUSCRIPT PREPARATION

To ensure a fair and unbiased review process, all submissions are to include an anonymised version of the manuscript. The exceptions to this are Correspondence, Book reviews and Obituary submissions. An anonymous version should not contain any author, affiliation or particular institutional details that will enable identification.

General article format/layout

- Manuscripts must be written in UK English.

- The manuscript must be in Microsoft Word format. Text must be single-spaced, in 12-point Times New Roman font, and contain no unnecessary formatting (such as text in boxes).
- Please make your article concise, even if it is below the word limit.
- Qualifications, ***full*** affiliation (department, school/faculty, institution, city, country) and contact details of ALL authors must be provided in the manuscript and in the online submission process.
- Abbreviations should be spelt out when first used and thereafter used consistently, e.g. 'intravenous (IV)' or 'Department of Health (DoH)'.
- Include sections on Acknowledgements, Conflict of Interest, Author Contributions and Funding sources. If none is applicable, please state 'none'.
- Scientific measurements must be expressed in SI units except: blood pressure (mmHg) and haemoglobin (g/dL).
- Litres is denoted with an uppercase L e.g. 'mL' for millilitres).
- Units should be preceded by a space (except for % and ºC), e.g. '40 kg' and '20 cm' but '50%' and '19ºC'.
- Please be sure to insert proper symbols e.g. µ not u for micro, a not a for alpha, b not B for beta, etc.
- Numbers should be written as grouped per thousand-units, i.e. 4 000, 22 160.
- Quotes should be placed in single quotation marks: i.e. The respondent stated: '...'
- Round brackets (parentheses) should be used, as opposed to square brackets, which are reserved for denoting concentrations or insertions in direct quotes.
- If you wish material to be in a box, simply indicate this in the text. You may use the table format –this is the *only* exception. Please DO NOT use fill, format lines and so on.

Research

Guideline word limit: 4 000 words

Research articles describe the background, methods, results and conclusions of an original research study. The article should contain the following sections: introduction, methods, results, discussion and conclusion, and should include a structured abstract (see below). The introduction should be

concise – no more than three paragraphs – on the background to the research question, and must include references to other relevant published studies that clearly lay out the rationale for conducting the study. Some common reasons for conducting a study are: to fill a gap in the literature, a logical extension of previous work, or to answer an important clinical question. If other papers related to the same study have been published previously, please make sure to refer to them specifically. Describe the study methods in as much detail as possible so that others would be able to replicate the study should they need to. Results should describe the study sample as well as the findings from the study itself, but all interpretation of findings must be kept in the discussion section, which should consider primary outcomes first before any secondary or tertiary findings or post-hoc analyses. The conclusion should briefly summarise the main message of the paper and provide recommendations for further study.

Select figures and tables for your paper carefully and sparingly. Use only those figures that provided added value to the paper, over and above what is written in the text.

Do not replicate data in tables and in text.

Structured abstract

- This should be 250-400 words, with the following recommended headings:
    - **Background:** why the study is being done and how it relates to other published work.
    - **Objectives:** what the study intends to find out
    - **Methods:** must include study design, number of participants, description of the intervention, primary and secondary outcomes, any specific analyses that were done on the data.
    - **Results:** first sentence must be brief population and sample description; outline the results according to the methods described. Primary outcomes must be described first, even if they are not the most significant findings of the study.

- **Conclusion:** must be supported by the data, include recommendations for further study/actions.

- Please ensure that the structured abstract is complete, accurate and clear and has been approved by all authors.
- Do not include any references in the abstracts.

Main article

All articles are to include the following main sections: Introduction/Background, Methods, Results, Discussion, and Conclusions.

The following are additional heading or section options that may appear within these:

- Objectives (within Introduction/Background): a clear statement of the main aim of the study and the major hypothesis tested or research question posed
- Design (within Methods): including factors such as prospective, randomisation, blinding, placebo control, case control, crossover, criterion standards for diagnostic tests, etc.
- Setting (within Methods): level of care, e.g. primary, secondary, number of participating centres.
- Participants (instead of patients or subjects; within Methods): numbers entering and completing the study, sex, age and any other biological, behavioural, social or cultural factors (e.g. smoking status, socioeconomic group, educational attainment, co-existing disease indicators, etc)that may have an impact on the study results. Clearly define how participants were enrolled, and describe selection and exclusion criteria.
- Interventions (within Methods): what, how, when and for how long. Typically for randomised controlled trials, crossover trials, and before and after studies.
- Main outcome measures (within Methods): those as planned in the protocol, and those ultimately measured. Explain differences, if any.

Results

- Start with description of the population and sample. Include key characteristics of comparison groups.
- Main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks.
- Do not replicate data in tables and in text.
- If presenting mean and standard deviations, specify this clearly. Our house style is to present this as follows:
- E.g.: The mean (SD) birth weight was 2 500 (1 210) g. Do not use the ± symbol for mean (SD).
- Leave interpretation to the Discussion section. The Results section should just report the findings as per the Methods section.

Discussion

Please ensure that the discussion is concise and follows this overall structure – sub-headings are not needed:

- Statement of principal findings
- Strengths and weaknesses of the study
- Contribution to the body of knowledge
- Strengths and weaknesses in relation to other studies
- The meaning of the study – e.g. what this study means to clinicians and policymakers
- Unanswered questions and recommendations for future research

Conclusions

This may be the only section readers look at, therefore write it carefully. Include primary conclusions and their implications, suggesting areas for further research if appropriate. Do not go beyond the data in the article.

APPENDIX 5: LINEAR REGRESSION ANALYSIS

Linear regression models were designed to estimate a linear relationship between unprompted and prompted composite knowledge scores for each knowledge category. Given that both unprompted and prompted variables did not follow normal distribution and such did not meet the assumptions for Pearson's correlation, the Spearman's correlation coefficient was computed to describe the monotonic relationship between unprompted and prompted variables (**Table 1**).

Table 1: Spearman's correlation coefficient measuring the rank correlation between rankings of prompted and unprompted knowledge scores.

		Coefficient	**P-value**
Breast Cancer	**Risk factor**	0.2443	0.0038
	Symptom	0.2246	0.0079
Cervical cancer	**Risk factor**	0.4319	0.0000
	Symptom	0.3942	0.0000

Table 1 shows a positive monotonic correlation between unprompted and prompted knowledge scores for breast cancer risk factors, breast cancer symptoms, cervical cancer risk factors and cervical cancer symptoms. However, the correlation between unprompted and prompted scores was weak for all categories given that all correlation coefficients fell below 0.5. As seen in **Table 1**, all Spearman's correlation coefficients were statistically significant as denoted by p-values below 0.05 (i.e. $p<0.05$). Linear regression models were then computed based on this premise of linear correlation between unprompted and prompted knowledge scores (**Table 2**).

Table 2: Linear regression analysis of the relationship between unprompted and prompted composite knowledge.

	Linear regression			**Model – Goodness of fit**	**Diagnostics - Residuals**	
	Coefficient	**P-value**	**95% CI**	**Adjusted R^{2*}**	**Normal distribution**	**Homoscedasticity**
Breast Cancer risk factors	1.675	0.003	0.597-2.754	0.0576	violates	violates
Breast cancer symptoms	0.608	0.002	0.232-0.984	0.0627	violates	violates
Cervical cancer risk factors	1.326	0.000	0.857-1.179	0.1808	violates	violates
Cervical cancer symptoms	0.887	0.000	0.542-1.231	0.1589	violates	violates

*The adjusted R^2 value was used to determine the goodness of fit for each linear regression models.

As seen above (**Table 2**) Linear regression coefficients for estimating the linear relationship between unprompted and prompted composite knowledge scores (for breast cancer risk factors, breast cancer symptoms, cervical cancer risk factors, and cervical cancer symptoms) were statistically significant as the 95% confidence intervals for each of the regression coefficients did not overlap zero (the null value) and p-values were less than 0.05 ($p<0.01$). However, the adjusted R^2 value shows that each of these models accounted for less than 20% of the variability of the response variable (prompted knowledge score) data about its mean.

Quantile-quantile plots and scatterplots of ordinary residuals versus predicted values were devised to determine if each model met the following linear regression assumptions: residuals are normally distributed and homoscedasticity respectively. All linear regression models were in violation of these assumptions (**Table 2**). Based on these results, it was reasonable to conclude that the coefficients and 95% confidence intervals yielded by the linear regression models may be inappropriate in describing the relationship between prompted and unprompted composite knowledge scores in our study.