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Study Protocol for Exploring the Health-Seeking Behaviors of Women with Advanced Breast Cancer in Southwestern Nigeria

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Abstract:

Globally, breast cancer is second most common cancer. Breast cancer is the most common cancer in women. It is the second cause of cancer-related mortality in women in high-resource income regions after lung cancer, and the most common cause of cancer-related deaths in women in low and middle-resource income regions. The leading cause of malignancy-related mortality among Nigerian women is breast cancer. In Southwestern Nigeria, women typically present with advanced stages of the illness, making the survival rate very low (48%). The aim of this study was to explore the women's health-seeking behavior from their perspective. This research was a qualitative study guided by a constructivist naturalistic orientation to knowledge development. The methodological approach adopted for the study was the interpretive description (ID). The study participants were thirty women with advanced stages of breast, defined as stages III and IV. The study setting was a large, tertiary, and referral hospital in Southwestern Nigeria. Data were collected through one-on-one, semi-structured audio-recorded, interviews guided by open-ended questions and from a demographic information form individual participant

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completed in advance. Data analysis of interview transcripts were inductive. Descriptive statistics were used to illustrate the study participants' characteristics. Findings revealed the study participants' health-seeking behaviors and the factors the women believe influence their health-seeking activities. Methodologically, this study advances the use of a qualitative approach to inquiry in seeking to explore and understand the health-seeking behaviors of women with advanced breast cancer in Southwestern Nigeria, a subject on which empirical literature is scarce.

Keywords: Advanced stages of breast cancer, health belief model, interpretive description, health-seeking behavior, women, Southwestern Nigeria, Nigeria,

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Introduction

Breast cancer is the fifth cause of global cancer-related death and it is the second cause of cancer-related mortality after lung cancer in high-resource regions of the world (Ferlay et al., 2015). In low and middle-resource countries, breast cancer is the leading cause of cancer-related deaths among women (Ferlay et al., 2015). Both the incidence and mortality rates of breast cancer have been rising in low and middle-resource income countries (Akarolo-Anthony, Ogundiran, & Adebamowo, 2010). In low-income countries, projections show that the incidence of breast cancer will continue to rise because of changes in population parameters and lifestyles (Porter, 2008). The breast cancer burden in low-middle income countries is growing, with survival rates much lower than those in high-income nations (Farmer et al., 2010; Parkin & Fernandez, 2006). Approximately 60% of breast cancer deaths occur in low-income, and economically developing countries (Jemal, Center, DeSantis, & Ward, 2010). In low-income countries, women present with the advanced stages of the illness (Jemal, Center, DeSantis, & Ward, 2010).

In Nigeria, breast cancer is the leading cause of cancer-related mortality among women (Adesunkanmi et al., 2006; Jedy-Agba et al., 2012; WHO, 2016), with 70-79% of women presenting with advanced stages, which are stages III and IV of the illness (Ezeome, 2010; Jedy-Agba, E., McCormack, Adebamowo, & dos-Santos-Silva, 2016). Research findings indicated that in low-income countries like Nigeria, women do not typically present until the illness has reached advanced stages, and delayed treatment represents significant problems for these women (Adesunkanmi, Lawal, Adelusola, & Durosimi, 2006; Oluwatosin & Oladepo, 2006). Furthermore, in the advanced stages of the illness, conservatory surgery is difficult to realize (Adesunkanmi et al., 2006; Adisa et al., 2011; Azubuike & Celestina, 2015).

In 2012, 27,304 cases of breast cancer, which accounted for 53% of other types of cancer, were diagnosed in Nigerian women while 13,960 deaths were recorded (GLOBOCAN, 2012; WHO, 2013). This figure amounted to a 48.9% survival rate. In the Western part of Nigeria, young women present with an aggressive subtype of breast cancer at the advanced stages of the illness (Adisa et a., 2012; Ntekim, Nufu, & Campbell, 2009; Pearson, 1963). The stage of breast cancer at diagnosis is a vital determinant of the illness survival rate; earlier stage disease presentation has often been associated with a better prognosis than later-stage disease presentation (Allemani et al., 2015). That is, advanced stage breast cancer has often been associated with a low survival rate (Ntekim, Nufu, & Campbell, 2009).

Delays in seeking appropriate treatment could result in advanced stage disease presentation. Presenting with advanced stages of the disease could be due to either patient-related factors or health system-related factors. Patient-related factors include age, education, economic status, sociocultural factors, knowledge about breast diseases, and health-seeking behaviors. Health system-related factors include the healthcare provider's characteristics, the waiting time for a cancer diagnosis, and lengthy referral protocols (Roy, Naher, Alam, Hanifa, & Sarkar, 2015).

Despite this high incidence of and mortality rates from breast cancer in Nigerian women, no empirical literature was found that explored the health-seeking behaviors of this population. The study sought to fill this gap in the literature by exploring the health-seeking behaviors

and reasons why women delay in seeking medical attention and care in the hospital, when they suspect they might have breast cancer.

Health-seeking Behaviors

Health-seeking behaviors are activities and initiatives in which individuals who perceive themselves to have health issues engage to resolve their perceived health problems. Health-seeking behaviors can either lead to a cure for the illness or reduce its effect on the individual's life. The measures undertaken are components of the health-seeking process (Chrisman, 1977). When individuals are ill, they are responsible for taking steps to restore their health by seeking help from appropriate and competent healthcare providers and return to full social functioning as soon as possible (Parson, 1951).

Health-seeking behaviors are often influenced by factors such as socioeconomic status, gender, age; type of illness, the influence of significant others and other social networks, and the quality of healthcare services (MacKian, 2003). Delays in obtaining proper diagnosis and care could result in the worsening of symptoms, potentially leading to adverse effects or outcomes (Afolabi, Daropale, Irinoye, & Adegoke, 2013). For healthcare providers, understanding the health-seeking behaviors and factors that influence health-seeking behavior is, therefore, critical, and crucial in providing patient-oriented services (Olenja, 2003).

The Objective of this Paper

The primary objective of this paper is: To present the methodology employed in exploring the health-seeking behaviors of Southwestern Nigerian women with breast cancer from the women's perspectives. The second aim is to share methodological ideas and insights with other students and researchers.

Research Questions

The study was guided by the following research question: How do women presenting with the advanced stages of breast cancer in Southwestern Nigeria describe their health-seeking behaviors?

Material and Methods:

The conceptual framework adopted for the study was the health belief model (HBM), The health belief model (HBM), a social psychology model proposed by Hochbaum, Rosenstock, and Kegels (1952). The HBM was developed within the US Public Health Services (Rosenstock, 1974; Ahmadian & Samah, 2013). The HBM attempts to explain an individual's behaviors in seeking to avoid disease, exploring motivation, perception, and the circumstances confronting the 'behaving' individual 131 (Rosenstock, 1974). The originators of the model believed that individuals' current situation and circumstances determine their actions (Rosenstock, 1966).

The methodological approach was the interpretive description (ID). Interpretive description is a qualitative research approach that can be used to investigate a problem originating from the practical setting and about which little is known. The findings from an interpretive description study can be practically used by the nurse and other professional in the applied professions. The study participants were women presenting with the advanced stages of breast cancer in a tertiary-university affiliated hospital in Southwestern Nigeria.

Methodological Approach

Study Design

A qualitative approach was adopted to explore and understand the activities in which Southwestern Nigerian women with advanced breast cancer engage to restore health or ameliorate their illness. This approach was chosen because a qualitative research approach enables the researcher to explore, examine, and describe people, their experiences, and behaviors in their natural environment (Creswell, 2007; Orb, Eisenhauer, & Wynaden, 2001). Interpretive description is a qualitative research approach that can be used to investigate a problem originating from the practical setting and about which little is known. The findings from an interpretive description study can be practically used by the nurse and other professionals in the applied professions. Interpretive description (ID), a research methodology developed by Thorne, Kirkham, and MacDonald-Emes (1997) guided the collection and analysis of the data. This approach was chosen because little has been documented about the health-seeking behaviors of women presenting with the advanced stages of breast cancer in Southwestern Nigeria. As Thorne et al. (1997 p. 173) contends, "Interpretive description contributes to the understanding of how people experience their health and illness and what nursing can do to make a difference." Thus, this research methodology seems ideal for determining the activities in which Southwestern Nigerian women who suspect they have breast cancer engage and the meaning of these activities to these women.

The ID research methodology was developed within the domain of nursing as a feasible alternative method of generating knowledge grounded in clinical nursing contexts (Thorne et al., 1997). Interpretive description captures themes and patterns embedded in personal experiences. The outcomes of ID studies can inform clinical understanding of phenomena (Thorne, Kirkham, & O'Flynn-Magee, 2004). Interpretive Description aligns with an interpretive naturalistic orientation, which acknowledges that human experience is both contextual and constructed (Thorne et al., 1997).

Rather than a specific set of procedures, the ID is a pragmatic approach, which uses a logic framework in implementing qualitative research techniques (Thorne, 2008). The logic framework is based on the reasoning applied at each decision-making point in the research process (Thorne, 2008). Beginning with the research question and proceeding through all the phases of the research study, the quality of the study relies on the goodness of fit between the research question, and the decisions made in conducting and concluding the study (Thorne, 2008).

Interpretive description is different from other traditional qualitative descriptive methodologies in that ID researchers look below the surface of clinical issues by exploring the meanings and the explanations that might be applicable in clinical settings (Thorne et al., 2004). ID involves an inductive reasoning process that generates findings that are well grounded within the data (Thorne, 2016).

Setting. The study participants were recruited from the oncology section of a large, urban tertiary, and university-affiliated hospital in Southwestern Nigeria. The hospital is a referral center for the whole country and West-African Sub-region. In the hospital, patients referred

from hospitals near and far usually receive comprehensive, and specialist assessment, diagnosis, quality treatment, and care of breast cancer and other illnesses. Data were collected at the oncology section of this hospital.

The study population. The population for the study was women presenting with the advanced stages of breast cancer in Southwestern Nigeria. This part of Nigeria is dominated by the Yoruba ethnic group. Southwestern Nigeria consists of 6 states—Lagos, Oyo, Ogun, Ondo, Ekiti, and Osun. Southwestern Nigeria is on the Gulf of Guinea beside the bay. The Niger river forms its northern and eastern boundaries. Much of the region consists of the savanna and the tropical forests. The people live in large cities and villages.

Sample selection. The purposeful sampling technique was used to select participants for the study. Purposeful sampling entailed the selection of information-rich participants (Patton, 2014). These participants can provide the researcher with a great deal of information about the issue under consideration. They must be willing to share this information with the researcher (Patton, 2014). The information shared by the participants shed light on the phenomenon under study providing the researcher with critical information and leading to an in-depth understanding of the issues of central importance in the study (Patton, 2014). The inclusion criteria for the study were: a) a diagnosis of either stage III or stage IV breast cancer, b) the ability to communicate in either the English or the Yoruba language or both, c) being of the female gender, and d) the ability to take part in an interview.

Participant recruitment procedure. A letter of support was requested from the authorities of the hospital where the data were collected. Ethical approval was obtained from the University of Saskatchewan, where the researcher is studying. Ethical approval was sought and obtained from the hospital where the data was collected. Permission to engage in data collection was obtained from the Chairman of the Medical Advisory Committee of the hospital. A letter of introduction and a copy of the ethical approval document were presented to the director of the oncology section to allow the researcher to gain access to prospective participants.

Two nurse clinicians at the oncology unit/ward who follow patients with advanced breast cancer were enlisted to serve as gate-keepers for the study. The researcher interacted with the gate-keepers before the commencement of the study to specify the characteristics and features of the study. These individuals were also provided with a reminder information sheet that described the purpose of the study, the inclusion and exclusion criteria, and other details. The gatekeepers assisted in recruiting participants in line with the inclusion and exclusion criteria of the study.

The information sheet was given to the gate-keeper nurses, who helped the other nurses in recruiting appropriate participants. The researcher's local phone number was made available to the gate-keeper nurses, so they could alert the researcher when a potential participant was identified. After the researcher had been notified about a prospective participant, the researcher called the research assistant, who reassessed the identified prospective participant and obtained the informed consent to participate in the study.

An appointment for an interview was scheduled at the consenting participant's convenience. The interview took place in a private room, which was previously arranged for the purpose in

the hospital. Before the interview began, information about the study were reviewed with each participant. The researcher stressed that the participant was free to change her mind and not take part in the study, and to do so without penalty.

Sample size. A sample of any size could be used in an ID study. The sample size adopted depends on the complexity of the issue under consideration. Many studies using this approach or some variation of it use small sample sizes between "five and thirty participants" (Thorne, 2016, p. 103). The researcher needs to put forward logical reasoning to justify the number of study participants, ensuring that the number of participants recruited for the study will generate credible and beneficial research outcomes (Thorne, 2016). In an ID study, data collection and analysis take place concurrently.

In the study, 30 participants were involved, a number guided by the saturation principle, also known as data redundancy. This phenomenon occurs when the researcher begins to hear the same comments again and again, can anticipate responses to the questions being asked, and realizes that no new information could enrich the emerging pattern from the data analysis (Thorne, 2016). At that point, according to Thorne (2016), the researcher understands that she or he has adequate participants to address the research question.

Data Collection

The goal of data collection in qualitative research is to describe a phenomenon from the participants' perspectives, typically through interviews and observation. In data collection, researchers must keep in mind the focus of the research and be clear about their roles as researchers (Creswell, 2007). To facilitate a productive interview, rapport must be established between the interviewer and the interviewee. However, a balance that enables interaction but also preserves objectivity must be sought and maintained (Smith, Flowers, & Larkin, 2009). The data collection for the study occurred in two phases: first, each participant completed a personal demographic form, and second, the researcher conducted an audio-recorded, face-to-face, one-on-one, semi-structured interviews with study participants. These interviews were guided by open-ended questions.

Participant demographic form. Each study participant who met the eligibility criteria and who consented to take part in the study were required to personally complete a researcher-designed demographic form. The demographic form obtained information on the participant's ethnic affiliation, age, educational attainment, yearly income, employment status, family history of breast cancer, and religious affiliation (Appendix A-1).

Interviews. Each study participant participated in one-on-one, face-to-face, semi-structured interviews guided by open-ended questions (Appendix B-1). The interviews were conducted by the researcher. The interview questions and protocol were designed by the researcher based on the information obtained from the literature review. Broad questions on the interview guide asked for information on the participant's breast changes, health-seeking behaviors, knowledge and perceptions of breast cancer, and significant health-seeking behavior challenges. The interview protocol was translated into the local language by a professional Yoruba language translator (Appendix B-2) and then translated back by another independent translator to ensure consistency with the original meaning.

The interview protocol was assessed for its suitability to collect the required data by two senior and experienced breast oncologists who have carried out research studies on breast cancer in the same context in Nigeria. To ensure the protocol was suitable and adequate to generate data on the health-seeking behaviors of women with advanced breast cancer, the protocol was pilot tested by interviewing similar breast cancer patients in the same setting as the study.

Once the protocol was deemed acceptable, study participants were interviewed in the language of their choice, either in Yoruba or English language. Questions on the health-seeking behaviors and factors that influenced their health-seeking behaviors were asked. Probes were used to encourage the participants to share the details of their experiences. The interviews were audio-recorded. Towards the end of the interview, a summary of the points that the participants shared were presented to them by the researcher for clarification. The duration of each interview ranged from 45-60 minutes, depending on the information the participants were ready to share.

Field notes were written by the researcher to describe the setting and the environment of the interview. Non-verbal communication and interactions between each participant and the researcher were observed and acknowledged. Immediately after the interview, the researcher documented her thoughts and feelings about the interview. The researcher also engaged in reflexivity to explore and expose her personal biases (Thorne, 2016), to ensure that these biases do not negatively influence the study.

Data Analysis

Descriptive statistics (means, median, and simple percentages) were used to analyze and illustrate the participants' characteristics. The individual audio-recorded interviews were transcribed verbatim by the researcher into a Microsoft Word document. The researcher transcribed the interviews while listening to the audio recordings and made necessary corrections. The data were cleaned by removing all the data that could identify an informant or any third party whose name was mentioned during the interview and replacing them with initials. The transcribed interviews in the Yoruba language were translated into the English language by the researcher. The translations were back-translated by another independent translator, who signed the confidentiality agreement, to ensure that the original meaning of the interviews was maintained. Individual participants' files were uploaded into NVivo, 12 software (QSR, International, 2018). The software was used to facilitate and organize the initial phase of analyzing the data into nodes.

Data analysis was inductive. Inductive data analysis entailed starting the data analysis process with immersion in the details and unique properties of the inquiry (Patton, 2014). It also involved knowing particular cases intimately, abstracting relevant common themes from these individual cases, and discovering central themes, patterns, and relationships (Thorne et al., 1997).

Reflexivity. The researcher engaged in reflexivity, by exploring and paying attention to whatever emerged, to produce usable knowledge (Thorne et al., 1997). By engaging in reflexivity, the researcher brought to the surface, acknowledges, and reflects upon her ideas, which might influence the design and implementation of the study (Thorne, 2016).

Ethical Consideration

The core principles that express the value of human dignity as laid down in the Tri-Council Policy Statement (TCPS-2, 2014) and the principles of research ethics in Africa (Kruger, Ndebele, & Horn, 2014), guided the conduct of the study. Ethical issues were addressed before, during, and after the study. Human subject research ethics approval was obtained from the University of Saskatchewan Research Ethics Review Board before starting the study. To enter the research environment and collect data for the study, ethical approval was obtained from the Joint Ethics Committee of the university and hospital where data were collected. Operational approval was obtained from the Chairman of the Medical Advisory Committee (CMAC) of the hospital.

Study prospective participants were fully informed of their rights as study participants. To safe guard against a possible power imbalance between the researcher, the gate-keeper nurses, and the study participants, a neutral person was employed as a research assistant, to obtain participants' informed consent to take part in the study. The research assistant, who was especially hired for this purpose, obtained informed consent from each participant. The written consent outlined the purpose of the study, the procedures to be followed, and potential benefits. Also, included in the consent form were information on data handling and storage, confidentiality, the right to withdraw consent to participate in the study at any time if the participant so wishes without any penalty, the right to answer only the questions the participant was comfortable with, permission to make an audio-recording of interview and for note-taking during the interview, ethics approval number, contact information of research supervisors, and that of the ethics board were given to each study participant. To ensure confidentiality, the participants' names did not appear on the demographic form and interview transcripts. Codes were used instead.

Rigor

Rigor in qualitative research refers to the truth value or trustworthiness of the study findings (Lincoln & Guba, 1985). Lincoln and Guba (1985) proposed four criteria for judging the integrity of the finding from a naturalistic inquiry: "credibility, applicability, consistency, and confirmability" (Lincoln & Guba, 1985, p. 290). Credibility is the extent to which the interpretations of the data are consistent with the ideas and meanings of the study participants. To guarantee that the results are credible, and to ensure that the findings and interpretations are those of the study participants, the researcher engaged in reflexivity as noted above. During and after the interview, the researcher asked for clarification of the participants' shared experiences to ensure that the points being shared were accurately understood. As the data analysis progressed, the initial interpretations of the findings were discussed with the study participants to clarify if they resonated with their experiences. Consistency involves the stability of the research procedures. Creating a detailed audit trail will enable another researcher to follow the same process. Applicability refers to the extent to which the findings could fit into contexts outside of the study situation, and the results could still be found meaningful (Sandelowski, 1986). In the study, applicability was ensured by providing a detailed description of the research context and background to research consumers. Confirmability refers to a bias-free research process. Confirmability was met by ensuring that the study findings were grounded in the data (Sandelowski, 1986).

Other methods of ensuring methodological rigor proposed by Thorne (2000) include the following: following the principles of epistemological integrity, analytic logic, and interpretive authority. Epistemological integrity entails guaranteeing defendable coherence between the research question, study design, and methods (Thorne et al., 1997). Analytic logic applies to the ability of an outsider to understand the decisions made by the researcher throughout all the phases of the research process (Thorne et al., 2004). Interpretive authority entails making sure the researcher's interpretations are accurate and illustrate some truth external to the researcher's biases (Thorne, 2016).

Results and Discussions

Breast changes were identified by the participants as the trigger for engaging in health seeking behaviors. However, many participants did not associate their breast changes with breast cancer. If women do not interpret their breast changes as signs of breast cancer, they are not likely to seek specialist and professional breast cancer care. Findings from the study also indicated that individual perceptions, cultural perceptions, interpretation of symptoms, spirituality, and the supportive role of family members, friends, and other social networks all influence the participants' health-seeking behaviors. The decision to engage in any health-seeking behavior was, in most cases, made at the family level. The desire to live outweighed the participants' challenges and difficulties, which they considered to be: stigma, financial difficulties, fear, and the side effects of breast cancer treatments.

The study disclosed the health seeking behaviors and the factors motivating the study participants to engage in specific health seeking activities. A model depicting the participants' health-seeking behaviors and another depicting the factors influencing the health-seeking activities of the study participants were developed. These models provide unique frames for nurses and other healthcare professionals to assess their patients' health-seeking behaviors as well as the factors influencing their health-seeking activities.

Significance and Implications for Nursing Practice

In Nigeria, late presentation of breast cancer, and limited treatment options have been assumed to contribute to the reasons for the poor prognosis of the disease. Exploring and understanding the health-seeking behaviors and the factors that influence the health seeking activities of Southwestern Nigerian women with the advanced stages of breast cancer could help identify the steps women take when they perceive breast ill-health and the actions that hinder an earlier presentation in the hospital. The awareness of the health-seeking behaviors can aid nurses and other healthcare professionals to know and understand their patients' health-seeking perceptions. This consciousness is important if health care professionals and patients are to successfully work together to better address patients' needs. This new understanding could also empower nurse clinicians and other breast cancer care stakeholders to recognize the critical areas and points contributing to delays in seeking medical attention for breast cancer and to develop and implement useful and contextually appropriate strategies, and interventions to encourage earlier presentation. Early presentation, diagnosis, and treatment of breast cancer might lead to improved treatment outcomes.

By using the models developed from this study as assessment tools, nurses and other healthcare professionals can have an in-depth understanding of their patients' health-seeking

behaviors and the rationale behind their health-seeking activities. This revelation can empower nurses and other professionals to provide culturally sensitive, contextually relevant individualized evidence-based nursing care required by their patients. The models can also serve as essential tools in planning and implementing evidence-based breast health counseling and health promotion activities that address the peculiar needs of their patients.

Conclusion

The aim of the study was to explore the health-seeking behaviors of women with advanced breast cancer in Southwestern Nigeria, from the women's perspectives. Interpretive Description was the methodological approach adopted to carry out the investigation. Interpretive description offered an invaluable methodological approach to examine and understand the experiences, perceptions, and interpretations of the health-seeking behaviors and factors women with advanced breast cancer in Southwestern Nigeria believe influence their health-seeking activities. The knowledge that emerged valued the participants' voices. This study supports the notion that nurses in the clinical setting listen to patients, hear their experiences, and factors they believe motivate the decisions made along their breast cancer illness trajectories. A strength of the study was that the participants were given the opportunity to choose the language of their preference for the interview, that is, ether in the local or the English language. The researchers understand both the local and the English languages. There was no need for an interpreter. The researchers, however, appreciated that the narratives of the participants were their interpretations and representations of their experiences.

Recommendations

The findings increase the awareness of the necessity for a comprehensive education about breast health and issues relating to breast cancer in Southwestern Nigeria. Nurses should provide education, counselling, and information to women and the general public, as well as plan and implement strategies to overcome barriers to seeking medical attention for breast abnormalities.

These findings suggest the need to raise breast health and breast cancer awareness, through public health campaigns, public education, and behavioral change interventions at the general community level. Public and community health practitioners could intensify health promotion campaigns in all categories of healthcare institutions and hospitals, to provide relevant information that could enable people to make informed choices. Increased knowledge and understanding of breast health, breast ill-health, and breast cancer-related issues could lead to a decrease in the incidence of breast cancer. Mass media coverage and effective media campaigns could assist in providing information on topics such as breast health and breast cancer. Therefore, training journalists on breast cancer and health reporting might be one way of addressing breast cancer-related myths and misconceptions. It could also, lead to earlier breast cancer identification, diagnosis, initiation of treatment, and a reduction in the mortality rates related to the illness.

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Appendix A: Participant Demographic Information Questionnaire

Please answer the following questions by checking a response or writing the answer in the space provided.

Date…….. Code no……..

1. What is your ethnic origin?

_____

2. What is your primary language?

☐ 1. Yoruba
☐ 2. Ibo
☐ 3. Hausa
Some other language
(Specify): _____

3. How old were you on your last birthday?

_____ Years old

4. What is your highest level of education?

☐ 1. Less than primary six
☐ 2. Secondary School
☐ 3. Some college/Associate's degree/technical certificate
☐ 4. Bachelor's degree
☐ 5. Graduate degree (e.g. Master's, PhD, JD)

5. What is your current employment status?

☐ 1. Working for pay at a job or Business
☐ 2. Looking for work, not currently employed
☐ 3. Not currently working and not looking for work

6. In 2017, what was your total family income from all sources? Was it:

- ☐ 1. Less than N50, 000. 00
- ☐ 2. N100, 000. 00
- ☐ 3. N200, 000. 00 or more
- ☐ 4. N500.000. 00?

7. Does anyone in your family or household have breast cancer or any other kind of cancer?

- ☐ 1. Yes
- ☐ 2. No

8. What was the time frame between when you first noticed breast changes and the when you reported in the hospital?

- ☐ Less than five months
- ☐ Five to less than ten months
- ☐ Ten to less than 15 months
- ☐ More than two years

9. What is your religious affiliation? ----------

Appendix A.2: Participant Interview Guide in the English Language

Good morning/ afternoon. How are you today? How is your health condition? Let me start by thanking you again for agreeing to take part in this study.

My name is ……. I am a graduate student from ……... As I explained to you earlier on, I am carrying out a study on the health-seeking behavior of women presenting with advanced stages of breast cancer in Southwestern Nigeria, and the factors that influence women in engaging in any health-seeking activity for the treatment of advanced stages of breast cancer in Southwestern Nigeria. This study is part of my PhD. Requirement. The aim of this study is to explore your health-seeking behavioral patterns, and any other factors that may be influencing health-seeking behavior for breast cancer among women. The goal of the study is to render an effective and comprehensive management of the disease to women. You have been purposely selected for this study.

I ask you to take this task seriously by sharing your opinions and ideas candidly and openly on the subject as this will facilitate the development of relevant interventions related to breast cancer in women.

The information collected will be confidential and it will be used for only the intended purpose of providing an integrated, comprehensive, and total management of breast cancer to women in Southwestern Nigeria.

To keep a more accurate record of our discussions and to ensure that it is accurately transcribed for my study as I explained to you before, I am proposing that we use a digital recorder. Do you mind if I use a digital recorder? (observe for any objection and if there in non, proceed). I can see that there is no objection to our using a digital recorder for this interview. I will also be jotting down some points in my notebook for the same reasons I discussed with you before. I thank you again for your cooperation.

If you want, and you request it, I will provide you with a copy of the transcript of the interview. If you want me to turn off the digital recorder at any point during the interview process, please let me know, I will do so. You do not have to answer any questions that you are not comfortable with. You are also free to stop the conversation at any time and withdraw from the interview without any consequences. Do you have any questions about the whole process before we proceed? (Participant will now be given the demographic form to fill out). This interview should take about 30-45 minutes.

1) Describe for me in as much detail as possible how you learned about your illness?
    i. Probe for the full story.
    ii. What were the signs that you saw? Probe for an explanation.
    iii. How did you respond to the observation?
    iv. What was your explanation of the signs and symptoms?
    v. Did you consult other people about your signs and symptoms?
    vi. If yes, who are these people that you consulted?
    vii. What advice did they give you?
2) Before you were diagnosed with breast cancer, did you know that you might be suffering from the disease?
    i. If no

ii. What then motivated or pushed you to seek for care in the hospital?

3) When people are diagnosed with breast cancer, they respond in different ways.
   i. Tell me how you responded
   ii. What steps did you take?
   iii. Tell me in detail what you did?
   iv. What activities did you engage in to manage the illness?

4) What does breast cancer mean to you?
   i. In your opinion, is breast cancer treatable?
      1. If yes, how? If no, why not?
      2. Is breast cancer curable?
      3. If yes, how? If no, why not?

5) How long did it take between the time you noted the signs and symptoms of the illness and the time you decided to seek health care in the hospital?
   i. Did you seek health care elsewhere before you decided to go for treatment in the hospital?
   ii. If yes, where did you go to seek for health care?
   iii. What reasons made you to go there?
   iv. Tell me about the kind of treatment you were given there?
   v. Was the treatment helpful?

6) What would you say was a major factor that influenced your decision to seek for health care in the hospital?
   i. After initiating treatment at the hospital, did you seek for health care elsewhere?
   ii. If yes, where?
   iii. What was your main reason for doing so?

7) What are the complications one is likely to get if one is not treated for breast cancer on time?

8) What in your understanding should a person do for the successful treatment of breast cancer?

9) Who has the final say on when and where you should take treatment when you are ill?

10) Do you have a particular person or place where you go to take treatment when you are ill?
   i. What motivates you to go there for treatment?
   ii. What other factors make you go there for treatment?
   iii. Tell me in detail the nature of the care you obtain there?
   iv. How pleased were you with the care and attention given to you?
   v. What was helpful?
   vi. What was not useful?

11) What factors determine where you go for treatment?

12) How far is your home from the hospital?
   i. Does the distance from your home to the hospital affect your going there for treatment?

13) For how long on the average, do you usually have to wait at the hospital before seeing a doctor?

14) What can you say about the answers and explanations you get from nurses and other healthcare workers to all the questions and issues related to your illness?
   i. How would you describe your relationship with the nurses?

15) What support do you get from your family and friends in taking care of your illness?
   i. Who would you say provides most of your care/ support?
   ii. What do they do?
   iii. What should be done to assist you?

16) What would you say are the major challenges you have been facing in taking care of your illness?
    i. How have you been addressing the challenges?
17) What have you learned from this illness?
18) What advice do you have for women having this kind of illness?
19) What can health care providers particularly nurses do to care more adequately for people with this kind of illness?
20) Do you think I should know anything else to understand the health-seeking behaviors you practice?
21) Towards the end of the interview, I will explain to the participant that I will transcribe the recorded interview, think, and reflect about it. I will ask if I can contact her again should I think I have any other questions. By the time the interview has been analyzed, several questions may have occurred to me. I will write down the questions. The second interview may help in the clarification of issues and points raised during the first interview.
22) Is there anything you would like to ask me or tell me?

Thank you very much for your participation.

Appendix A.3: Participant Interview Guide in The Yoruba Language

ATỌKA ÌBÉÈRẸ ỌRỌ FÚN ÌPÀDÉ ÌWÁDÌÍ ỌRỌ LÓRÍ ÀWỌN OBÌNRIN TÍ N WÁ ÌWÒSÀN ÀRÙN ỌMÚ TÓ TI WỌRA NÍ GÚSÙ-ÌWỌ̀OÒRÙN NIGERIA.

Atọ́ka Ìwádìí Ọ̀rọ̀ Náà

Ẹ kú ìkàlẹ̀ o. Òní áá san wá o. Ṣé ara le? Ara áá yá o. Ṣíwáju jẹ́ kí n dúpẹ́ lọ́wọ́ yín tí ẹ gbà láti kópa nínú ẹ̀kọ́ yìí.

Orúkọ mi ni …….. Èmí jẹ́ akẹ́ẹ̀kọ̀ọ́ àgbà láti …….. Gẹ́gẹ́ bí mo ti ṣàlàyé ṣíwájú, èmi n ṣe ìwàdìí ẹ̀kó lórí àtiṣe àwọn obìnrin alárùn ọmú tó ti wọra ní Gúsù-ìwọ̀oòrùn Nigeria, pẹ̀lú àwọn ohun tí àwọn obìnrin bẹ́ẹ̀ n ṣe láti wá ìmúláradá. Ìwádìí ẹ̀kọ́ yìí jẹ́ apá kan pàtàkì nínú iṣẹ́ PHD tí mo n ṣe lọ́wọ́. Ohun tí ẹ̀kọ́ yìí n lépa ni láti wo àwọn ọ̀nà tí ẹ n gbà fún ìtọ́jú, àti àwọn ọ̀nà mìíràn tí àwọn ènìyàn n gbà wá ìwòṣàn àrùn ọmú láàárín àwọn obìnrin. Ohun tí ẹ̀kọ́ yìí n lépa ni láti fun àwọn obìnrin ní ìtọ́jú tó kúnjú fún áìsàn náā. A sì mọ̀ọ́mọ̀ yàn yín fún ẹ̀kọ́ yìí ni.

Mo n rọ̀ yín kí ẹ gba iṣẹ́ yìí ní ọ̀kúnkúndún, kí ẹ sọ tinú yín àti ìrísí yín ní kedere lọ́rí ọ̀rọ̀ yìí, nítorí ṣíṣe bẹ́ẹ̀ la ṣe lè ṣiṣẹ́ borí àrùn ọmú obìnrin.
Ọ̀rọ̀ ajọṣọ wa yìí wà ní àṣíríbò, ìlépa àṣekápá àrùn ọmú obìnrin ní apá Gúsù-ìwọ̀oòrùn Nigeria nìkan ni a ó lò ó fún.

Kí ọ̀rọ̀ ajọṣọ wa yìí lè wà ní pípé mo dábāá kí a lọ ẹ̀rọ agbọ̀rọ̀sílẹ̀ (digital recorder). Ṣé kò sẹ́ni tó lòdì sí lílò ó? (Ṣàkíyèsí ẹni tí kò bá fẹ́. Bí kò bá sí, máa bá ọ̀rọ̀ lọ). Mo rí i pé kò sẹ́ni tí kò fẹ́ bẹ́ẹ̀. Èmi náà yóò máa kọ kókò ọ̀rọ̀ wa sínú ìwé ọwọ́ mi fún ìdí kan náà ti mo ti bá yín sọ tẹ́lẹ̀. Mo dúpẹ́ fún ìsowọ́pọ̀ yín.

Bí ẹ ba n fẹ́, tí ẹ bá bèèrè fún un, èmi yóò fún ẹni bẹ́ẹ̀ ní àdàkọ àbájáde ìwádìí tí a n ṣe yìí. Bí ẹ bá n fẹ́ kí n pa ẹ̀rọ agbọ̀rọ̀sílẹ̀ bí a ti n bá ìwádìí ọ̀rọ̀ wa lọ, kí ẹ jẹ́ kí n mọ̀. Èmi yóò sì ṣe bẹ́ẹ̀. Ẹ kò ní láti dáhùn ìbéèrè tí kò rọrùn fún yín. Àyé sì wà láti dánu ọ̀rọ̀ dúró nígbà kúùgbà, àní láti jáde nídìí ọ̀rọ̀ láìsí ohun tí yóò tẹ̀yìn rẹ̀ wá. (Wàyìí ni a ó fún àwọn tó wà ní ìpìdé ní ìwé iye ènìyàn láti kọ ohun tí a bèèrè níbẹ̀).
ìwádìí ọ̀rọ̀ yìí yóò gba àsìkọ̀ àádọ́rùn-ún (90) ìṣẹ́jú (wákàtí kan àti ìṣẹ́jú mẹ́ẹ̀ẹ́dógún).

1. Ṣàlàyé ní kíkún fún mi ohun tí ẹ ti mọ̀ nípa àìsàn yín.
    i. Ṣe ìwádìí gbogbo ìtàn náà.
    ii. Àwọn àmì wo lẹ rí? Wádìí fún àlàyé.
    iii. Kí ni ẹ ṣe nígbà tí ẹ rí àwọn àmì náà?
    iv. Kí ni ẹ ka àwọn àmì náà kún?
    v. Njẹ́ ẹ fi ìrírí àwọn àmì náā lọ ẹni kẹ́ni?
    vi. Bí ó bá jẹ́ bẹ́ẹ̀ ni, àwọn ta ni ẹ fi lọ̀?

vii. Kí ni ìmọ̀ràn tí wọ́n fún yín?

2. Kí a tó ṣe ìbẹ̀wò yín wò fún àrùn ọmú, njẹ́ ẹ mọ̀ pé ó ṣeéṣe kí ó jẹ́ pé àrùn ọmú ló wà lára yín?
   i. Bí bẹ́ẹ̀ kọ́
   ii. Kí ló mú yín wá sí ilé ìwòsàn fún ìmúláradá?

3. Lẹ́yìn ṣíṣe ìwàdìí tí a sì mọ̀ pé àrùn ọmú ló n ṣe àwọn ènìyàn kan, oríṣiríṣi ọ̀nà ni ọkàn wọ́n fi n gbà á.
   i. Ṣọ fún mi bí ọkàn yín ti gbà á.
   ii. Àwọn ọ̀nà wo ni ẹ gbà?
   iii. Ṣọ fún mi lẹ́ṣẹlẹ́ṣẹ ohun tí ẹ ṣe.
   iv. Ṣíṣe wo ni ẹ ṣe fún ìtọ́jú àìlera náà.

4. Kí ni àìsàn ọmú jásí fún yín?
   i. Njẹ́ ẹ rò pé árùn ọmú ṣeé wòsàn?
   ii. Bí bẹ́ẹ̀ ni: Báwo? Bí bẹ́ẹ̀ kọ̀: Nítorí kí ni?

5. Báwo ló ti pẹ́ tó kí ẹ tó wá fún ìtọ́jú ní ilé ìwòsàn lẹ́yìn ìgbà tí ẹ ti rí àwọn àmì àìsàn náà?
   i. Njẹ́ ẹ lọ ìbòmìírān fún ìtọ́jú kí ẹ tó pinnu láti wá gba ìtọ́jú ní ilé ìwòsàn?
   ii. Bí bẹ́ẹ̀ ni: Níbo ni ẹ ti lọ gba ìtọ́jú náā?
   iii. Kíló mú yín lọ ibẹ̀?
   iv. Ṣọ fun mi, irú ìtọ́jú wo ni ẹ rí gbà lọ́hùn-ún?
   v. Njẹ́ ìtọ́jú náà ṣe yín lánfàànī?

6. Kí ni ìdí pàtàkì tí ẹ lè ṣọ pé ó mú yín wá fún ìtọ́jú ní ilé ìwòsàn?
   i. Lẹ́yìn ìbẹ̀rẹ̀ ìtọ́jú ní ilé ìwòsān njẹ́ ẹ tún lọ ibònìíràn fún ìtọ́jú?
   ii. Bí bẹ́ẹ̀ ni: Níbo?
   iii. Kí ni ìdí pàtàkì tí ẹ fi ṣe bẹ́ẹ̀?

7. Àwọn ìlọ́júléra wo ló lè ṣẹlẹ̀ bí a bá pẹ́ láti gba ìtọ́jú fún àrùn ọmú.

8. Kí ni ẹ mọ̀ tó yẹ kí a ṣe fún ìtọ́jú tò péye fún àrùn ọmú?

9. Ta ni aláṣẹ ibi tó yẹ kí ẹ ti lọ gba ìtọ́jú nígbà tí ara yín kò bá dá?

10. Njẹ́ ẹni kan tàbí ibi kan wà pàtó tí ẹ ti n gba ìtọ́jú nígbà tí ara yín kò bá yá?
   i. Kí ló fà á tí ẹ fi n lọ ibẹ̀ fún ìtọ́jú?
   ii. Kí ni àwọn ohun mìíràn tó n mú yín lọ síbẹ̀ fún ìtọ́jú?
   iii. Ṣọ fún mi lẹ́ṣẹlẹ́ṣẹ irú ìtọ́jú tí ẹ n rí gbà lọ́hùn-ún?
   iv. Báwo ni ìtọ́jú ọ̀hùn-ún ti tẹ́ yín lọ́rùn tó?
   v. Njẹ́ ó ṣèrànlọ́wọ́?
   vi. Kí ni kò wúlò níbẹ̀?

11. Àwọn ohun wo ló lè mú yín mọ ibi tí ẹ ti lè lọ gba ìtọ́jú?

12. Báwo ni ibùgbé yín ti jìn sí ilé ìwòsàn tó?
    i. Njẹ́ ọ̀nà jínjìn ibúgbé yín sí ilé ìwōsān jẹ́ ohun ìdínà fún yín ní lílọ gba ìtọ́jú níbẹ̀?
13. Báwo ni ẹ sábà ti n dúró pẹ́ tó kí ẹ tó lè rí Dòkítà ní ilé ìwòsàn?

14. Kí ni ìrísí yín nípa ìdàhùn àti àlàyé àwọn Nọ́rsì pẹ̀lú èyí ti àwọn oníṣẹ́ ìtọ́jú n fún yín lórí àwọn ọ̀rọ̀ tó jẹmọ́ àìlera yín?
    i. Kí ni ẹ lè sọ nípa ìṣesí àwọn Nọ́rsì pẹ̀lú yín?

15. Ìrànlọ́wọ́ wo ni ẹ n rí gbà láti ọwọ́ ìdílé yín pẹ̀lú àwọn ọ̀rẹ́ yín fún ìwòsàn yín?
    i. Ta ni ẹ lè pè ní agbátẹrù ìnáwó fún ìtọ́jú yín?
    ii. Kí ni wọ́n n ṣe?
    iii. Kí ni a lè ṣe láti ràn yín lọ̀wọ́?

16. Kí ni ẹ lè sọ pé ó jẹ́ àwọn ìṣòro pàtàkì tó dojúkọ yín nínú ìtọ́jú àìsàn yín yìí?
    i. Bàwo ni ẹ ti ṣe n dojúkọ àwọn ìṣòro yín náà?

17. Ẹ̀kọ́ wo ni ẹ rí kọ́ nínú àìsàn yìí?

18. Ìmọ̀ràn wo ni ẹ ní fún àwọn obìnrin tí àìsàn yìí n ṣe?

19. Kí ni àwọn oníṣẹ́ ìwòsàn, ní pátàkì àwọn Nọ́rsì, kí ni wọ́n lè ṣe láti ṣètọ́jú tó gbéṣẹ́ tunbọ̀ sí i fún àwọn onírú àìsàn yìí?

20. Njẹ́ ohun mìíràn wà tí ẹ rọ pé ó yẹ kí n mọ̀ kí ìṣesí yín nínú irú áìsàn yìí lè yé mi dáradára?

21. Nje ó ní ohun kóhun tí ẹ bá fẹ́ bèèrè lọ́wọ́ mi?

Mo dúpẹ́ púpọ̀ lọ́wọ́ yín fún ìkópa yín nínú ọ̀rọ̀ yìí.

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