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## Field Report: Collecting Data on the Influence of Culture and Indigenous Knowledge on Breast Cancer Among Women in Nigeria

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Culture has been shown to influence health beliefs and health-related behaviors because it influences the type of information women have been exposed to, as well as their resources for interpreting such information. This field report summarizes my approach to understanding how culture influences breast cancer screening behaviors among women seeking care at a local non-profit clinic in Lagos, Nigeria.

Keywords: *Culture; Breast Cancer Screening; Nigeria; Survey Design*

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### Background

Breast cancer is the most common cancer among African women (Busolo and Woodgate 2014) and is mostly prevalent in young, premenopausal women in Nigeria (Anyanwu 2000; Adesunkanmi et al. 2006; Ihekweba 1992). The biggest cause of breast cancer mortality in this country has been cited as low screening levels, which lead to late-stage diagnosis (Busolo and Woodgate 2014; Anyanwu 2000; Holcombe, Weedon, and Llin 1999). One study found that 80.6 percent of breast cancer patients had been diagnosed in late stages (Adesunkanmi et al. 2006). Over the past fifteen years, knowledge and awareness of breast cancer risk factors, screening methods, and treatments have been studied among different populations in Nigeria. Low levels of breast cancer knowledge have been found in both healthcare workers and the general population. This leads to a decreased likelihood that women will undergo screening, which means that in many cases, symptoms are ignored until late stages.

Culture has been shown to influence health beliefs and health-related behaviors because it impacts the type of information women have been exposed to, as well as their ability to interpret such information (Spector 2002). Very little data exists that describes how culture influences beliefs and attitudes toward breast cancer and breast cancer screening in Nigeria. Cultural influences, however, likely correlate to screening behaviors for breast cancer. This field report summarizes my approach to understanding how culture influences breast cancer screening behaviors among women seeking care at a local, non-profit clinic in Lagos, Nigeria.

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### Health and Healthcare in Nigeria

According to the World Health Organization, the current life expectancy at birth in Nigeria is fifty-three years for men and fifty-six years for women. The health status of a country is commonly measured by its child and maternal mortality rates. The 2015 maternal mortality rate per 100,000 births in Nigeria was 814, compared to fourteen in the United States, and the neonatal mortality rate per 1,000 live births was 34.3 in Nigeria and 3.6 in the US (World Health Organizations and United Nations 2015). Infectious diseases are the most common cause of death in Nigeria (World Health Organizations and United Nations 2015) with lower respiratory infections leading in 2012, accounting for 13.9 percent of deaths, followed by HIV and malaria. As of 2012, deaths due to HIV were 128.7 per 100,000 population (2.5 in the US) and deaths due to malaria were 106.9 per 100,000 population (World Health Organizations and United Nations 2015). In 2014, non-communicable diseases such as cardiovascular disease, cancer, and diabetes were estimated to account for twenty-four percent of total deaths (World Health Organization 2014). Nigeria does not have a national population based cancer registry or national cancer screening guidelines (World Health Organization 2014).

The provision of health care in Nigeria is run by the three tiers of government: the federal, state, and local governments (Omoruan et al. 2009). The local government areas (LGAs), similar to those in US counties, manage the primary health care system with support from their state ministries of health and private practitioners. The state ministry of health manages the secondary health care system (Omoruan et al. 2009). Patients are referred to this level from primary health care providers. Specialty services are available at different divisions of the state, such as diagnostic and rehabilitation services. The state government is also responsible for running general hospitals. The federal government manages the tertiary health care system by coordinating federal medical centers, university teaching hospitals, and specialist hospitals (Omoruan et al. 2009). The federal government also works with nonprofits and private practitioners to provide these services. There are 33,303 general hospitals, 20,278 primary health centers and posts, and fifty-nine teaching hospital and federal medical centers in Nigeria. However, it is important to note that 70 percent of the health care is provided by private vendors and only 30 percent by the government (Omoruan et al. 2009).

The Nigerian government spends comparatively less on health than other African countries. In 2014, the total expenditure on health was 3.7 percent of the nation's gross domestic product (Bhardwaj 2016) and of that, only 0.9 percent was publicly funded while most of Nigeria's health spending was in the private sector (Bhardwaj 2016). In addition to inadequate funding, health access is only 43.3 percent (Onwujekwe et al. 2010). This could be attributed to the fact that 55 percent of the population lives in rural areas (Omoruan et al. 2009), yet the bulk of the health workforce is concentrated in urban, tertiary health care facilities.

### Research Setting

The study took place at the Optimum Cancer Care Foundation (OCCF), a non-profit founded to address the issue of low breast cancer screening and awareness in Lagos, Nigeria. OCCF provides subsidized breast cancer screening without long waiting periods or crowds associated with public hospitals. In addition, OCCF also conducts weekly seminars on risk factors, signs, and symptoms associated with breast cancer.

I interviewed women attending the clinic for breast and/or cervical screening or treatment. Women were eligible to participate if they were eighteen years or older and able to speak English or Nigerian Pidgin. Pregnant women and those unable to give verbal consent were excluded. Women who met the age and language criteria were identified as potential participants based on their clinic registration form. Potential participants were then invited to participate in the study via a verbal recruitment script. The clinic registration fee (approximately three US dollars) was covered as compensation for participating in interviews. Women who did not have to pay the registration fee were given goods worth three US dollars as an incentive for participation.

I asked the women for the following demographic information before the start of each interview: age, marital status, employment status, highest level of education, religion, and state of origin. Program participants were asked to identify any barriers that may have hindered them from being screened or understanding the seminars, and to understand the role of culture and indigenous knowledge. Previous studies on the Nigerian population have used surveys that asked simple yes or no questions. This was deemed appropriate for simplicity for the sake of participants in other studies. However, for this study, open-ended questions were used for a broader understanding of the influence of culture on health seeking behavior. Questions were designed to ascertain participants' knowledge in three areas: risk factors for breast cancer and common symptoms, methods of early detection and diagnosis, and attitudes and practices toward breast cancer. Questions included the following: How did you hear about OCCF?; Why did you come in for screening?; Have you ever been screened before?; What do you believe causes breast cancer?; Do you know anyone who has had breast cancer?; How do local foods, beliefs about medicine, and behaviors contribute to breast cancer risk?; and, What do you think would prevent you from coming back to OCCF?

The chosen research setting was a convenient recruitment site for women who fit the eligibility criteria. The setting was also opportune to conduct interviews, as private offices were available. Some issues with the research setting occurred when the interview room needed to be used. In that case, the interview was conducted outside of the building but within the clinic compound. The interview was still in a private setting; however, noise from traffic would sometimes be a distraction. I interviewed ninety-four women during my time in Lagos.

### **Development of Interview Questions**

My knowledge of the local culture, a combination of questions used in other similar studies (Phillips, Cohen, and Moses 1999; Nwankwo et al. 2011), and an African centered cultural model (Airhihenbuwa 1990) were used to create the semi-structured interviews. I used two rounds of pilot testing. This was done to ensure that the questions were easily understood and made sense to women of different backgrounds, to identify problems with the survey that may lead to biased answers, and to make sure all women interpreted the questions in the same way. In the first round, a random sample of five women were asked the survey questions. The order of questions was adjusted and some questions were simplified. In the second round of pilot testing, women in a different branch of the breast cancer screening clinic were interviewed. These women fully represented the target population of the study and probes were developed and used in subsequent interviews.

### **Training Interviewers**

I trained two interviewers to assist with the study. One interviewer was not able to start the study after the training, which resulted in my conducting the study with only one other individual. Interviewers needed to avoid using words, gestures, and facial expression that may limit or bias answers from participants. Interviewers were trained to be as neutral as possible with tone and expressions, especially since respondents needed to choose their own words or terms. Interviewers also needed to be able to ask follow-up or probe questions that did not make the respondent feel defensive. Finally, interviewers needed to refrain from asking too many questions at once so as to not confuse the participants. Interviews were conducted by Bilikisu Elewonibi and a local volunteer at the clinic, both of whom were familiar with local language, customs, and traditions.

### **Conducting Interviews**

The length of interview times ranged from twenty to forty minutes and each interview was dictated on a tape recorder. Each respondent was given an ID number and no personal identification information was collected. During the interview, notes were taken to record certain occurrences, such as if a respondent started to cry or looked angry. A few respondents unconsciously switched from English to speaking Yoruba (one of Nigeria's national languages). At the discretion of the interviewer, the participant was asked to either repeat what she had said in English or the interviewer simply translated what the participant said. In a few other cases, some respondents could not express themselves in English or did not know the English term for a feeling or expression. In these cases, the interviewer translated what the participant was attempting to say. A convenient sample of women were interviewed until theoretical saturation has been reached, or the point at which no new information was identified (Creswell 2013). After each day of interviews, all recordings were uploaded to a password protected laptop, as well as a cloud folder. Bilikisu Elewonibi listened to all interviews at the end of the day or the following day. On the basis of these observations, the questions were revised, the order of questions was switched, or the interview strategy as a whole was changed.

### **Results**

From these interviews, I found that culture both encourages and inhibits breast cancer screening among women in Lagos. Illnesses were often thought to occur as a result of superstitious beliefs and these beliefs in turn drove health decisions and treatment choices. Many women believed there was a spiritual cause for breast cancer and hence there could only be a spiritual solution. One woman discussed how she had been told that an acquaintance died from breast cancer because someone had shot a spiritual arrow from her village into her breast. A few women mentioned prayer as the most important "cure" for any illness. Other women said that as long as they prayed and had faith, they would be protected from getting breast cancer. The women who felt that breast cancer was caused by supernatural forces did not see breast cancer screening as relevant and would not encourage other women to receive screenings. Finally, many women discussed how they did not visit a physician or hospital when they were sick but instead chose to self-medicate. It appeared that the idea of being ill was seen as weakness and there was a lack of preventive medicine culture among these women.

Even with these inhibitions, there were many positive aspects of culture that encouraged breast cancer screening. Some women had received warnings from friends or family that getting screened would “invite cancer” into them. Many of these women acknowledged that while some in the community would frown on their choice, they had faith in god and would not be diagnosed with cancer even after being screened. In addition, they felt that due to this faith they would easily be healed by a physician if breast cancer was found. They acknowledged the importance of seeking out medical services, such as screening, but had their faith and religion to help cope with whatever the results of testing showed. In fact, many women had stated that they were encouraged to come to the screening center by their pastors or other religious leaders who had spoken about the importance of screening.

### **Reflection**

I had two very different types of experiences with women during the interview process. Some women were very open and willing to discuss their experiences with the health care system and their perceptions about breast cancer. They were willing to talk about how their friends, family, and community would react if they knew they had come to a breast cancer clinic. These women were not afraid to talk about the negative or positive reactions they had received from the people they worked with, spouses, or friends. On the other hand, some women were very shy and reluctant to talk about these issues. They had to be prompted and probed to elaborate on their responses and they seemed to be uncomfortable throughout the whole interview. Another observation was that when given the opportunity, many women continued to talk well after the interview was over. Many asked me questions about other health issues they or another family member had. One woman asked me about breast cancer perceptions in the United States and how was it different from what I had heard so far in Nigeria.

From my experiences in Nigeria, culture can be a very powerful influence in the realm of health, particularly breast health. Breasts are not necessarily seen as sexual organs in this culture, but the idea of going to the hospital for preventive breast health was negatively perceived by some. The role of the community and organized religious institutions can be leveraged in changing these perceptions. If these places encouraged more women to seek screening, awareness and service utilization would increase. In addition, the strong social support mentioned by numerous women should continue to be encouraged as it can be used to help spread awareness of the benefits of breast cancer screening and dispel some of the false rumors surrounding treatment. Furthermore, women and mothers are respected in Nigerian culture, and many are in control of their health care decisions. More emphasis needs to be placed on the importance of women’s health and health interventions should focus on direct appeals to women—highlighting the importance of screening and early detection as the most effective method of treating breast cancer.

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