ENHANCING BREAST CANCER EARLY DETECTION IN MALAWI: A MIXED METHODS STUDY TO UNDERSTAND KNOWLEDGE AND PREFERENCES

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ABSTRACT

Racquel Elizabeth Kohler: Enhancing Breast Cancer Early Detection in Malawi: A Mixed Methods Study
to Understand Knowledge and Preferences
(Under the direction of Stephanie B. Wheeler)

Breast cancer is the most common cancer in sub-Saharan Africa, and the number of new cases
is increasing. Although early diagnosis is a vital factor for treatment outcomes, it is rare in resource-limited
settings like Malawi. Currently there is insufficient evidence on how breast cancer knowledge among
Malawians influences early detection. The purpose of this dissertation was to better understand
knowledge, beliefs, and preferences related to breast cancer in Malawi.

The first analysis entailed eliciting beliefs and perceptions related to breast cancer and cancer
care to explore various factors influencing diagnosis and treatment initiation. Results from interviews with
breast cancer patients indicated that individual, interpersonal, provider, and health system factors
influenced access to care and led to long delays from when a woman noticed symptoms to when she
inferred illness, decided to seek help, reached the health facility, and received care.

The second analysis involved interviews with community women and health workers to identify
factors influencing early detection behaviors and preferences. Based on the responses, we developed a
discrete choice experiment (DCE) to elicit women's preferences about early detection. Cognitive testing
demonstrated the feasibility of administering a DCE in a low-literacy population where DCEs and early
detection are uncommon.

Finally, we conducted a survey among community women to assess knowledge, beliefs, and
preferences related to breast cancer and early detection. Our results showed that less than half of the
sample was aware of breast cancer. Misconceptions about causes were more commonly reported than
established risk factors. The results from the DCE suggest future interventions should provide clinical
breast exams and education in convenient settings.

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This dissertation provides a framework for understanding breast cancer delay in sub-Saharan Africa, identifies what women know about breast cancer, and indicates what women value about early detection interventions. Taken together, the findings can be used to tailor future cancer services and educational programs to meet local needs. Policy, practice, and future research should focus on training providers and educating the public about breast cancer signs and symptoms and also expanding access to clinical breast exams for symptomatic women to improve early detection and treatment outcomes.

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LIST OF ABBREVIATIONS

BSE	Breast self-examination
BHGI	Breast Health Global Initiative
BWS	Best-worst scaling
CBE	Clinical breast examination
DCE	Discrete choice experiment
HBM	Health Belief Model
HCW	Health care worker
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
KCH	Kamuzu Central Hospital
LMIC	Low- and middle-income country
MoH	Ministry of Health
RLS	Resource-limited setting
SSA	Sub-saharan Africa
TA	Traditional authority
VIA	Visual inspection with acetic acid
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

Breast cancer is the most common cancer in sub-Saharan Africa (SSA), and the number of new cases is expected to nearly double by 2030 (1). In SSA, breast cancer disproportionately affects premenopausal women, who typically present with advanced incurable disease and experience long delays between symptom onset, diagnosis, and treatment initiation (2, 3). Although data from SSA may be country-specific due to sociocultural and economic differences, studies suggest reasons for late diagnosis include misconceptions about the disease, fears of mastectomy, low awareness of cancer, and poor access to providers (4-6). As a result of late diagnosis, mortality rates are high.

The existing breast cancer literature provides little insight into women's use of breast cancer detection and care services in Malawi, one of the most resource-limited countries in SSA. Currently, cancer prevention and control in Malawi is limited; the health care system infrastructure cannot support multidisciplinary cancer care, so patients are left with few treatment options. Despite breast cancer becoming a significant health problem, no national control program exists. The potential of clinical downstaging through breast cancer early detection has not yet been explored in Malawi and the optimal strategy remains unclear. Malawian breast cancer patients have symptom durations of 8 months on average, are diagnosed at young ages, and have aggressive tumor types (7). There is a critical need to characterize local beliefs, knowledge, and preferences regarding breast cancer services in order to better understand how and why women do or do not seek breast health services. These data are vital to help address this gap and to develop culturally appropriate strategies to improve early detection.

The overall objective of this dissertation was to understand Malawian women's beliefs, knowledge, and preferences related to breast cancer and early detection. In order to frame awareness messages and to develop sustainable cancer programs, we must identify what women know and value

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about breast health care. We conducted the following three aims to better understand breast cancer beliefs, knowledge, and preferences among Malawian women:

Aim 1. Explore local factors that influence breast cancer beliefs and early detection behaviors through interviews with breast cancer patients, providers, and women from the community. There is a paucity of research regarding breast cancer in Malawi. In fact, few studies have investigated emerging chronic health problems, such as cancer, due to the country's burden of infectious diseases such as HIV, tuberculosis, and malaria. To our knowledge, this is the first study on breast cancer beliefs and knowledge in Malawi. This aim entailed eliciting attitudes, beliefs, and perceptions related to breast health and breast cancer to understand the unique and nuanced determinants of early detection and diagnosis. In-depth interviews were conducted with 20 breast cancer patients, 10 health care providers, and 20 women from local communities. Transcripts from patients were analyzed separately and are presented in Chapter 4. Transcripts from provider and community interviews were used to help identify appropriate attributes for the preference assessment tool (Aim 2), and the analyses of these qualitative data are included in Chapter 5.

Aim 2. Develop a preference assessment tool to elicit Malawian women's preferences related to breast cancer services. Preference assessment is an innovative technique that helps patients clarify choices and values, provides information about important factors that influence early detection use, and helps inform future delivery models and program planning. To our knowledge, no previous studies have developed a discrete choice experiment (DCE) for breast cancer early detection in Africa. In addition, few studies have used DCEs among vulnerable international or low-literacy populations. Themes that emerged from provider and community interviews conducted in Aim 1 were used to develop a DCE with locally relevant characteristics of early detection services. We designed a DCE using Sawtooth Software (Sequim, Washington) in order to determine important attributes of early detection interventions. We conducted cognitive interviews with eight low-income and/or low-literacy women before incorporating the tool into the questionnaire (Aim 3). Results from this DCE development process are presented in Chapter 5.

Aim 3. Administer a questionnaire to assess women's current knowledge, beliefs, behaviors, and preferences related to breast cancer and early detection services. Health-seeking

behaviors and preferences in SSA, may be influenced by very different social and cultural factors than in the United States. Therefore, we administered a cross-sectional questionnaire to 213 women to examine knowledge related to breast cancer signs, risk factors, risk perception, behaviors, and preferences. Survey responses were used to assess associations between women's socio-demographic characteristics and knowledge, risk-perception, behaviors, and early detection preferences. This aim provided data that can be used to tailor interventions to promote early detection and also determined what services women preferred and how they should be delivered. Results of these survey analyses, including the DCE, are presented in Chapter 6.

This dissertation adds to the literature in three major ways: 1) it addressed an emerging public health problem, breast cancer, which had not yet been examined in Malawi; 2) it employed an innovative technique – preference assessment – to align demand and delivery of services; and 3) it explored developing a DCE in a vulnerable, low-literacy population. The findings can help inform the development of public health interventions to improve breast cancer control in Malawi and other countries in SSA.

This dissertation is organized as follows: Chapter 2 describes the current literature regarding breast cancer burden, knowledge and beliefs, and screening and early detection in SSA. Chapter 3 discusses an overview of the methods and includes a description of the rationale, setting, study design, sample, data measures, and analytic approach for each aim. Chapters 4-6 are manuscripts from three analyses: Chapter 4 analyzed reasons for delay from the patient interviews, Chapter 5 analyzed provider, community, and cognitive interviews to develop the DCE and determine the feasibility of administering it with the knowledge survey, and Chapter 6 analyzed the knowledge, beliefs, and preferences survey results. The three manuscripts are in preparation for submission to peer-reviewed journals. Chapter 7 provides a review of the study findings and summarizes the policy, practice, and research implications. References are listed in a complete bibliography at the end of the dissertation.

CHAPTER 2: LITERATURE REVIEW

Cancer Burden in Africa

Cancer is the leading cause of death worldwide, and the burden is increasing in developing countries. Over half of all new cases and more than two-thirds of all cancer deaths occur in developing countries (8). The gap between developed and developing countries is expected to widen as incidence trends continue to grow. In addition, large disparities in case fatality highlight the challenges developing countries face in treating and managing cancer; estimates suggest that the ratio of mortality to incidence is 75%, compared to 46% in developed countries (9). Structural, environmental, biological, and social factors all contribute to disparities in cancer morbidity and mortality.

Global estimates from the World Health Organization (WHO) indicate that as many as 1.5 million of the predicted 17 million new cancer cases in 2020 will occur in Africa (10). The growing and aging populations, widespread poverty, and limited cancer resources, contribute to the rising cancer burden in the region.(2) With people living longer and populations adopting unhealthy behaviors, including increased alcohol and tobacco use and high-fat diets, the cancer burden is expected to increase across the continent as more countries urbanize.

In a region where HIV, malaria, tuberculosis, and maternal mortality plague populations, cancer control and cancer care programs struggle to get funding and attention from international donors and health ministries. Many countries face an increasing double burden of infectious diseases and non-communicable diseases, and are poorly equipped to tackle competing health needs. Although some African countries have established cancer control efforts, most face challenges to prevent, diagnose, and treat cancer in resource-limited settings (RLS). Few hospitals are equipped to care for cancer patients, and standard treatments from developed countries are rarely available in RLS due to the high costs of

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therapies, specialized equipment, and training required. Additionally, health care workforce shortages leave many countries without oncology specialists. As a result of these challenges, the quality of cancer care in SSA varies tremendously. Research is needed to develop country-specific, practical approaches to cancer control in order to combat this growing public health problem, especially because resources are scarce.

Among women, the most common cancers in SSA are breast cancer, cervical cancer, and liver cancer (1). In most African countries breast cancer is the most common, but cervical cancer is still frequently diagnosed cancer in many countries as shown in Figure 1.

Figure 2.1. Most common cancer sites among females in Africa by country (GLOBOCAN 2012) (1)

However, reports of new cases may be underestimated due to poor access to care, limited health systems infrastructure, and few cancer data systems, particularly in rural areas. Reliable cancer data are

scarce: only about 1% of African populations are covered by cancer registries; however, GLOBOCAN estimates represent the most accurate data available given the limited number of national registries in Africa (1, 10, 11). Indeed, these data show that breast and cervical cancer are major public health challenges among many African countries.

Table 2.1. Age-standardized incidence and mortality rates per 100,000 population per year for common female cancers

	Incidence, ASR		Mortality, ASR	
	Africa	SSA	Africa	SSA
Breast	36.2	33.8	17.3	17.2
Cervix	20.4	34.8	17.5	22.5
Liver	5.8	6.4	5.6	5.1

Notes: ASR, age standardize rate
GLOBOCAN 2012 data (12)

Breast Cancer Burden

Globally, breast cancer is the most frequently diagnosed cancer and the leading cause of death among females (13). Although incidence rates in developed countries are much higher, breast cancer incidence in developing countries is increasing at a faster pace and it is more fatal (14). Mortality to incidence ratios are correlated with gross domestic product, and over 75% of breast cancer deaths occur in developing countries (15, 16). Poorer countries fare worse; the ratio of breast cancer deaths to new cases in developing countries was 0.39 and 0.54 in SSA (17).

In SSA, breast cancer recently surpassed cervical cancer as the most common cancer, and the number of new cases is expected to nearly double by 2030 (1, 18). Generally incidence is higher in urban settings, but there are significant geographic variations in incidence rates mainly due to the availability of early detection services and differences in reproductive factors.

Research has identified numerous factors that affect a woman's risk of developing breast cancer. Current evidence indicates that age, nulliparity, late age at first birth (after 30), long menstrual history, and exposure to hormonal therapies increase the risk of breast cancer (19). Other risk factors that increase risk of breast cancer include a personal or family history, genetic mutations (i.e., BRCA1, BRCA2), and biopsy-confirmed hyperplasia are well documented (20, 21). Lifestyle behaviors such as diet and exercise also play a role in breast cancer risk (22). The literature also suggests that breastfeeding is an important factor that protects women from breast cancer.

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Recently many African countries have seen a shift in reproductive patterns as a result of improved socioeconomic conditions, including lower fertility, delayed childbearing, earlier menarche, and aversion to exclusive breastfeeding (1). Additionally, many African countries are experiencing increases in physical inactivity, obesity, and alcohol consumption (23), all of which can contribute to increased breast cancer risk. However, breast cancer in SSA and other developing countries may have a different etiology than breast cancer in women from developed Western countries (16).

Breast cancer disproportionately affects young, premenopausal women in SSA, who typically are diagnosed between 35 and 45 years of age (24). Younger women in SSA also tend to have high-grade, aggressive tumors and present with advanced incurable disease. Late diagnosis often results in ineffective curative efforts, which contribute to high breast cancer mortality rates across SSA. For example, studies from Uganda, Sudan, Tanzania, and Nigeria indicate that 61-91% of patients present with stage III or IV disease (16).

Although histopathological characterizations of breast tumors in SSA are lacking, some studies suggest that African women are more likely to have hormone-receptor negative tumors (25). Studies from South Africa, Nigeria, Senegal, and Tanzania suggest that breast tumors in black Africans are predominantly large, late stage, high-grade tumors. Reports indicate a large variation in hormone receptor status: 27-80% of tumors from multiple African countries were estrogen receptor negative (26-28). Additionally, a large portion of tumors are triple negative tumors which are more aggressive and drive the high mortality rates in the region (25). Based on these clinical features and the fact that women are often diagnosed in their thirties and forties, evidence suggests a more rapid course of disease in African populations with a poor prognosis (16). Many of the women diagnosed in the region have poor health outcomes: five-year survival is only 32% in SSA compared to 81% in the United States (29).

Poor health outcomes are also the result of a majority of breast cancer patients experiencing long delays between symptom onset, diagnostic evaluation, and treatment initiation (2, 3). Myths about the availability and affordability of effective interventions may also deter women from seeking care for women's health issues and cancer diagnostic evaluations until symptoms have advanced. However, variation in countries' health system infrastructure and cancer resources may lead to differences in women's perceptions of cancer treatment and outcomes. Indeed, in a region where access to health care

and cancer treatment are limited, it is critically important for women to know where and how to seek breast health care.

Breast Cancer Awareness and Beliefs

One of the main reasons for the high rates of breast cancer mortality is poor public awareness of breast cancer. Generally in SSA, awareness of breast cancer signs/symptoms, treatment options, and potential curability is low (30). Little knowledge of cancer risk factors and signs/symptoms has been linked to delays in health-seeking behaviors, which can also lead to poor health outcomes (13, 31). Surveys from northern Africa indicated people were largely unaware of signs/symptoms or risk factors of breast cancer. In some populations less than half of women surveyed knew that a breast lump was a sign of cancer (5, 6). However, previous surveys are largely hospital-based samples and may not be generalizable to other populations.

Social norms and cultural beliefs may play a role in women's breast cancer beliefs and can have adverse effects on women's interpretation of disease symptoms. Cultural misconceptions about causes of breast cancer drove Ethiopian women to seek care from traditional healers (32). In some areas of Africa supernatural etiology, such as curses and witchcraft, have been commonly noted as a cause of breast cancer, especially among women living in rural villages (6, 33). Other misconceptions about causes include exposure to certain plants, objects, or health conditions. For example, in Ethiopia many breast cancer patients believed the disease was caused by "bad air" and breastfeeding problems (32). Also, women from rural villages in Kenya and Ghana believed that keeping money or mobile phones inside a bra was a physical cause of cancer (6, 33). However, due to differences in religious beliefs and cultural traditions, it is unclear whether the same misconceptions are common across countries.

Many women, unaware of breast cancer risk, ignore symptoms until they become severe (34). It may not uncommon for breast cancer patients to report they were unaware that the initial lump, rash, or pain they noticed was a sign of cancer, as studies have found in Ethiopia (32, 35). Additionally, feelings of hopelessness, fear, and fatalism have been reported among women in some populations (32, 36, 37).

While these studies provide helpful information about perceptions from some African populations, none explicitly focus on breast cancer in Malawi, one of the most resource-limited countries in the world. Evidence regarding local beliefs is needed to deepen our understanding of how to improve early detection

of breast cancer in Malawi. After assessing local knowledge of breast cancer and social or cultural obstacles to early detection, behavioral and educational interventions can be designed to counteract low levels of awareness and cultural perceptions to promote early detection and improve breast cancer outcomes.

Breast Cancer Screening and Early Detection

The literature is clear that early diagnosis leads to more effective treatment and better outcomes, and in many developed countries, screening is associated with early diagnosis. However, it is important to differentiate screening from early detection. Screening focuses on systematically finding cancer in *asymptomatic* populations who are generally healthy and have not sought medical intervention (38). Early detection, however, is when breast cancer is diagnosed when a woman presents to a health care provider with a symptom, and the disease is caught at a time when it can be treated with curative intent (20). Educating the public and providers on the early signs and symptoms of breast cancer can be part of an early detection program without providing screening services (39). Recognizing that screening requires significant investments, and is not feasible is most SSA countries, this dissertation focuses on early detection and begins to explore opportunities for screening.

The high breast cancer mortality rates in SSA underscore the importance of increasing early detection, diagnosis, and treatment. Although mammography proved effective in developed countries, the technology is not widely available in SSA due to high costs of infrastructure and human resources it requires (30, 40). Additionally, mammography may not be appropriate for detecting breast masses in SSA because a large proportion of women present with ulcerated, visible, or easily palpable tumors that are evident without mammography. Because mammography is not affordable or feasible in much of SSA, countries must implement practical early detection strategies to improve mortality rates (41).

Evidenced-based, resource-stratified guidelines on awareness, diagnostic, and therapeutic options have been developed through a consensus panel process by the Breast Health Global Initiative (BHGI) (42). For settings with basic resources, the BHGI recommendations include promoting breast health awareness, including early signs/symptoms and breast self-exam (BSE), and using clinical breast examination (CBE) to detect cancer (34). It is well established that breast cancer detected early and treated promptly has a higher cure rate. Thus, in RLS where early detection is not common, knowledge of

signs/symptoms is crucial to prompt women to seek care, get diagnosed, and receive referrals for treatment (34, 39, 41).

Evidence from observational studies about BSE is conflicting, but no study has demonstrated that BSE detects breast cancer at earlier stages or improves survival (43, 44). Data from randomized BSE intervention trials in Russia and China did not show significant differences in mortality. However, breast cancer awareness was already high in both of the trial populations, suggesting BSE is not beneficial in those settings. If a randomized trial on BSE were conducted in SSA, however, it might have different results because of low awareness of the disease and symptoms; it might also have more opportunity to reduce mortality because so many patients present at advanced stages. Nevertheless, many doctors and health organizations promote breast health awareness. In general they suggest that women should be aware of their breasts in order to notice changes and seek medical care; some also suggest routine BSE. Still, expert health groups like the WHO and US Preventive Services Task Force agree that no evidence has shown the benefits of BSE outweigh the risks, and therefore do not encourage BSE (20, 21).

Instead, most advocates of early detection endorse CBE as an appropriate approach in RLS although the effect of CBE has not been rigorously examined in SSA. BHGI suggests that CBE is the most resource-appropriate detection strategy for many developing countries (42). And preliminary results from some studies suggest that CBE may be a valid screening tool. Additionally, CBE is well-suited for RLS because it can be performed by trained non-medical personnel and can be easily decentralized. However, the optimal strategy and age to start screening remain undetermined because evidence about CBE efficacy is controversial, and long term data from randomized trials are not yet available.

Early results from trials in India and Egypt suggest that stage distribution was better in the screened groups (45, 46). Similarly, a study in Malaysia saw reductions in late stage presentation of breast and cervical cancers from a combined screening trial (47). And a recently published pilot study on community-based awareness and door-to-door CBE screened over 10,000 women in rural Sudan with community health volunteers. In the intervention population, a majority of women (12/17) with cancer were diagnosed with early stage disease, compared to all three of the confirmed cancers from the control group which were all advanced disease (40, 48).

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However, problems with acceptance of screening and detection methods, follow-up diagnostic procedures and treatment have been documented in multiple studies, highlighting the importance of complex cultural factors that influence participation and compliance. For example, in the Muslim Sudanese villages, participation was lower when the health volunteer was from a different village, suggesting the importance of having a trusted, female community health volunteer perform the CBE (40). And in the Mumbai trial, approximately 100 female workers had to make multiple door-to-door visits to motivate and persuade women to attend screening and comply with follow-up (49). A similar trial in the Philippines was stopped because women refused to attend follow-up appointments (41). Understanding local perceptions of screening and early detection methods is critical to address social and cultural obstacles to early diagnosis.

In RLS, clinical downstaging is an important alternative to screening and can be integrated in pre-existing health programs. Clinical downstaging focuses on detecting cancer early in symptomatic patients and ensuring women with early signs of breast cancer seek medical help and receive appropriate care. For much of SSA, increased awareness of the early symptoms of cancer and promoting the benefits of early detection are commonly noted as necessary first steps to improve early detection (34, 40, 49). However, the most appropriate approach to breast cancer awareness campaigns must be determined for each country, and remains unknown in Malawi. Recognizing what Malawians know and value about breast cancer and early detection will allow tools and programs to be developed and tailored to a population's need.

Knowledge and Practices of Breast Cancer Detection Methods

Despite numerous reproductive health knowledge surveys being administered in Malawi, no studies on breast cancer or breast cancer detection strategies have been conducted to date. Evidence from other studies on general beliefs about cancer among Africans has suggested that individual knowledge, perceptions, and beliefs play a significant role in women's cancer practices. In general, women who are knowledgeable about breast cancer are more likely to practice BSE or have a CBE or mammogram.

However knowledge about breast cancer and detection methods may also be affected by additional factors such as social norms about preventive care and local beliefs. For example, although

women in Kenya were familiar with CBE, they were usually examined due to a mastitis complaint not a well visit (33). The low-income women from rural Kenya also reported they did not think it was necessary to have a breast exam if there were no problems or pain (33). Other studies of breast cancer screening in Africa reported common barriers to health-seeking behaviors including privacy concerns, religious beliefs, preferences for alternative medicine, and fear of rejection by spouses (3, 37), (42). Women may also face obstacles in accessing breast cancer services due to transportation, economic hardships, and women's roles in society (6, 50, 51). In some countries, women reported feeling more responsible to their family roles than leaving the home for their own care. For example, caregiving for children and elders, cooking, and farming responsibilities influence their ability to access personal health services (52-54).

Health Care Providers' Role in Early Detection

Evidence from developed countries indicates that providers play a critical role in cancer screening participation and early detection. Thus, knowledge and training about the disease and its detection strategies are crucial for health care providers to communicate and promote cancer detection to the public. Female health workers such as nurses, midwives, and community health workers are often trusted sources of health information for African women, especially for reproductive health issues, so their understanding of breast cancer could be essential to improve early detection (33, 40). For these primary care providers, awareness of breast cancer symptoms and beliefs about breast cancer early detection practices are particularly important to address among female patients to avoid delayed referrals for diagnostic evaluation and treatment.

Low levels of breast cancer knowledge have also been reported among health care providers in Africa (55-57). Data from Nigeria, Morocco, Ghana, and Ethiopia suggest that knowledge of breast cancer among nurses, nursing students, and other clinicians is low. These studies indicate a need for increasing breast cancer education for health care providers to improve their knowledge of breast cancer risk factors, signs/symptoms, and detection strategies.

Delayed Diagnosis

Many complex individual, sociocultural, and health system factors can affect delays in breast cancer diagnosis. Although there are varying definitions of different types of delays, previous research

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has shown that a delay of three months can have profound effects on prognosis and survival (58, 59). Patient delay is typically considered a prolonged delay from noticing a symptom to presenting to a provider. In comparison, provider or health system delays from presentation to treatment are also important obstacles to breast cancer care (60). And in general the literature suggests that women who are poor are more likely to experience delays, and often for a much longer time.

Multiple studies report that a majority of women across SSA wait more than six months to seek care after noticing a breast problem, some with persistent problems for 2 years (3, 37, 61). A review of delayed breast cancer presentation in developing countries found strong evidence that being poor, unmarried, widowed, divorced, or having low education increased barriers to care; poverty was the most important barrier across studies. The review also found evidence that women who live in rural areas, use alternative treatments, and have low breast cancer awareness tend to experience more frequent and longer delays (60).

Research suggests sociocultural reasons for delayed breast health-seeking behaviors include ignorance of symptoms, stigma of disease, superstition and misconceptions about cancer, self-denial, and fear of mastectomy (4-6). Additionally, multiple studies have reported women delaying reproductive care and cancer screening because they were embarrassed to show their bodies to a male doctor (6, 33, 48, 50).

Long delays are often reported with using traditional herbal medicines; some women do not seek medical attention until traditional herbal remedies fail. For example, studies from Nigeria indicated that women were concerned about mastectomy, preferred to try traditional treatment, and nearly half of patients who were recommended mastectomy refused the surgery (37, 62). However, mastectomy is not the only procedure that influences delays; some patients are hesitant to have a biopsy and refuse the diagnostic procedure. In addition, some women who are diagnosed may not follow-up on the results and fail to attend subsequent appointments for treatment.

Economic and health system barriers to breast care include limited availability of treatment options and poor access to providers, especially for women living in rural villages. Many women travel long distances to reach a health facility, leaving work and family responsibilities, and often incurring a

significant cost for transportation. The high cost of care has also been reported as a burden for some women in need of medical services and drugs to manage the disease (63).

These are important factors to consider, however, there may be significant variation in barriers to care due to differences in country-specific cultural and economic factors. Therefore, research is needed to examine reasons for delayed presentation in order to address individual, social, and health system barriers to care in Malawi and encourage early detection.

Malawi

Malawi is a small, landlocked country located in southeast Africa; it shares borders with Tanzania, Mozambique and Zambia. It is one of the smallest, but most densely populated countries in SSA, with a population of approximately 16 million people, 11% of which is infected with HIV (64). The country is made up of three regions: the Northern region is sparsely populated, the Central region is where the capital city, Lilongwe, is located, and southern region is home to the largest commercial city, Blantyre. There are 28 districts within the country, which are divided into traditional authority (TA) areas and villages (65). Approximately 84% of the population lives in rural areas (66).

Malawi faces an unfortunate combination of economic development challenges including poverty, drought, disease, and a lack of critical resources. About 79% of the population has access to an improved water source, but only 11% of households have a drinking source at their house. In rural areas, most household rely on a tube well or borehole for water (65). The most recent demographic and health survey data indicated that household access to improved sanitation facilities is lacking. Eight percent of houses use an improved latrine (not shared with other households) and most (75%) use a pit latrine without a covering (65).

The 2012 GDP per capita was estimated to be $900 and health expenditures made up roughly 8.4% of GDP (66, 67). The formal sector employs only a small portion of Malawians, thus a majority of the population work in the informal agriculture sector. In general, the economy is in a fragile state, and the Kwacha, the local currency, has depreciated considerably although the cost of living has increased. The labor market in Malawi struggles with a severe human capacity problem due to a large number of unskilled and uneducated workers. Although school attendance has been increasing, there are differences in education by gender and residence; more women than men have never attended school,

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and those in rural areas are more likely to have no formal education (65). Secondary education was introduced to Malawi in 1940, however, recent reports indicate that a quarter of students drop out after the first year of primary school (64) and more men than women complete secondary school (65).

Not surprisingly, Malawi is heavily dependent on foreign aid; over half of the GDP is from foreign donors. Many health and human service projects and other structural reforms are underway throughout the country to improve development. However, the current economic climate and growing population leave much of the population in poverty and over a quarter of Malawians are considered ultra-poor (68).

Malawi's health system is tiered like most other African nations with a centralized referral hospital system and free basic public services. Each district has a hospital which receives referrals from local health centers. The tiered hospital system encourages patients to seek primary care at the small, local health centers, but they may be referred to district-level hospitals or one of four central hospitals for tertiary care (67, 69). In addition, privately-run facilities and hospitals run by non-governmental organizations usually charge fees, but sometimes offer additional services, such as private birthing rooms. Providing health care in Malawi is challenging due to the lack of trained personnel and poor infrastructure; there are roughly 2 physicians for every 100,000 people (66). In general, deficits arise from lack of health workers, supply stock-outs, and lack of basic utilities.

The health system challenges are exacerbated by the prevalence of HIV/AIDS and unhealthy behaviors, chronic malnutrition, and frequent outbreaks of diseases. Average life expectancy has increased since 2000, with improved access to HIV antiretroviral treatment; 2012 WHO data indicate that life expectancy at birth is 59 years (66). However, HIV/AIDS was by far the leading cause of death and disability in 2012 (66) Non-communicable diseases (NCD) like cancer are becoming significant causes of morbidity and mortality and the prevalence of common risk factors is increasing nationwide. A recent study of NCD risk factors found that overweight, obesity, and physical inactivity were more frequently reported among women than men and more common in urban than rural areas (70). NCDs are estimated to account for 28% of all deaths in Malawi and are expected to increase to up to 40% by 2015 (71). As HIV mortality decreases and NCD risk factors affect more Malawians, cancer prevention and control activities will become increasingly important.

Cancer Care in Malawi

Cancer is a growing public health problem in Malawi. Due to the high prevalence of HIV, AIDS-defining cancers including Kaposi's sarcoma, cervical cancer, and non-Hodgkin lymphoma are very common in Malawi (72). The WHO estimates that Malawian women bear a large burden of disease and every year almost 8,000 Malawian women will be diagnosed with cancer (8). According to a recent review of data from 2007-2010, the most common cancers among females in the national cancer database were cervical cancer, Kaposi's sarcoma, esophageal cancer, breast cancer, and non-Hodgkin lymphoma (73).

Table 2.2. Common types of cancers among females in Malawi

	Proportion of new female cancer cases	Incidence, ASR
Breast	4.6%	3.5
Cervix	45.4%	33.6
Esophagus	8.2%	6.8
Kaposi's sarcoma	21.1%	11.9
Non-Hodgkin lymphoma	4.1%	1.7

Notes: ASR, age-standardized rate per 100,000 population per year
Data summarized from Msyamboza et al. (73)

Malawi does not have a formal national cancer control plan as defined by WHO guidelines; however, the Ministry of Health (MoH) has launched various initiatives, often with international donors, to focus on preventing, screening, and treating certain cancer types. For example, in 2004, Malawi established a national cervical cancer screening campaign, and recently private donors have conducted human papillomavirus (HPV) vaccine pilot studies (74). But there is no national breast cancer awareness campaign or screening program and little is known about the breast cancer burden in Malawi. Retrospective studies of cancer registries suggest that breast cancers make up 5.5-8% of cancers in the country (73, 75). The 2012 Globocan estimates suggest that the mortality to incidence ratio is higher for Malawi (0.52) compared to SSA regional estimate (12).

Diagnostic capacity has improved recently, but there are only two government-run pathology laboratories in two central hospitals (76). Most patients are diagnosed after clinical examination, chest X-ray, ultrasound, and biopsy. Because imaging machines are expensive and require regular maintenance, staging is often done with surgery not CT scans. However, less than 18% of cancer cases in the national

registry were histologically confirmed; 50% had some clinical investigations and 33% were diagnosed based on history and physical clinical examination (73).

There are no radiotherapy facilities in the country, therefore, mastectomy is the most effective treatment because breast conserving therapy would require adjuvant radiation (77). A small number of Malawians may be referred to neighboring countries or India for radiation services; however, the referral process is complex.

Malawi also faces challenges in cancer management due to a scarcity of trained oncology professionals and drug shortages. Two national teaching hospitals in the central and southern regions are where a majority of chemotherapy services are provided, however, drug supply is inconsistent and many patients do not receive the full combination of chemotherapy agents as prescribed. Drugs are available at no cost to the patient through the government hospital pharmacies, however, when they are out of stock, patients must purchase drugs from private pharmacies. Neoadjuvant chemotherapy is used to treat some women with locally advanced breast cancer to decrease tumor size prior to surgery, but there are no clear guidelines for determining which tumors are resectable and eligible for treatment. Tamoxifen is available and can be used to treat hormone-receptor positive tumors; however, immunohistochemistry is not routinely performed to determine hormone-receptor status.

Patients with metastatic disease receive palliative care through hospitals, pharmacies, and local non-governmental organizations. However, few, if any, support services exist to help patients and their families navigate the fragmented health system and cope with the psychosocial aspects of a cancer diagnosis and treatment.

Expanding Women's Cancer Detection Services

Opportunities exist to increase access to breast cancer early detection services in Malawi. If advanced tumors could be down-staged by earlier detection, many women's lives could be saved. There is potential to integrate breast cancer detection and diagnostic services at several levels. Providers working in maternal and reproductive health clinics already offer a variety of preventive services including family planning, sexually transmitted infection testing, and cervical cancer screening. Additionally, midwives, nurses, and community health workers have been trained to conduct cervical exams in neighboring countries and are trusted by women in many communities (17, 78). Although there are some

differences in how cervical cancer and breast cancer screening programs are implemented (e.g., frequency and starting age), they share similar features and could be linked to improve early detection of both cancers. However, downstaging capacity and provider practices regarding breast cancer detection methods have not yet been examined in Malawi.

Currently the Malawian reproductive health guidelines recommend providers conduct CBE annually on all women (79). The guidelines also indicate that education on BSE and risk factors to increase awareness of breast cancer should be disseminated. However, breast cancer early detection and educational campaigns have not been widely implemented. Without a systematic approach to early detection of breast cancer, Malawi remains vulnerable to high rates of advanced disease, poor survival outcomes, and an escalating public health problem.

Patterns of general preventive service use are low (80), and perceptions of breast cancer and early detection among Malawians remain unclear. Because no previous studies have explored early detection of breast cancer in Malawi, this gap in the literature lends itself to exploratory research methods to address nuances specific to Malawian women. If breast cancer awareness programs are implemented in the future, then it is critical that current beliefs, knowledge and preferences concerning breast cancer and its early detection measures of the target audience are understood. This dissertation study makes a major contribution by integrating qualitative and quantitative methods that will generate a deep understanding of breast cancer in light of local realities.

CHAPTER 3: STUDY DESIGN AND METHODS

Overview and Rationale

Successful breast cancer early detection and awareness interventions must address local women's knowledge and preferences; therefore this study was a necessary prior step to designing future randomized trials in SSA. Given the increasing burden of breast cancer in the region and uncertainty regarding optimal detection strategies in RLS, it is critical to ensure that any resources directed towards developing interventions or programmatic strategies are based on what Malawian women need and want.

The <u>overall objective</u> of this dissertation was to understand Malawian women's beliefs, knowledge, and preferences related to breast cancer and early detection strategies. The <u>rationale</u> for this research was that many women are diagnosed with advanced stage disease, therefore we must identify opportunities to increase early detection of breast cancer in order to improve cancer outcomes. We need to understand what women know and value about breast health care in order to enhance early detection interventions and to develop sustainable cancer programs. This dissertation examined local beliefs, knowledge, and preferences that influence breast health care access and behaviors. Overall, the findings provide culturally-sensitive information about Malawian women's knowledge and stated values that can be used to inform how future cancer services and public health education should be tailored to meet local needs.

Based on a review of breast cancer knowledge and attitudes in Africa and drawing upon the social contextual framework and Health Belief Model, this dissertation relied on a mixed methods approach to examine Malawian women's beliefs, knowledge, and preferences of breast cancer and early detection. The in-depth interviews in Aim 1 allowed exploration and insight into people's beliefs, perceptions, and opinions about breast cancer, including patients, providers, and the general community of women, and identified local factors that were important to include in the preference assessment tool.

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Aim 2 entailed designing and testing a preference assessment tool. Finally, Aim 3 used a quantitative survey approach to measure Malawian women's knowledge about breast cancer and their early detection behaviors and preferences. Taken together, these quantitative and qualitative approaches allowed us to explore the wide array of what women know and believe about breast cancer and what they desire regarding early detection services.

Study Setting

This dissertation was conducted through UNC Project Malawi, a 20-year long partnership with UNC and the Malawi MoH. The collaboration is internationally recognized for HIV and infectious disease research, and has a growing global oncology research program. UNC Project is based in Lilongwe, Malawi's capital, in the central region of the country. Women of diverse social, economic, and ethnic backgrounds reside in the central region. Additionally, Lilongwe district is comprised of rural, urban, and peri-urban TA areas.

The central referral hospital for the region, Kamuzu Central Hospital (KCH), is located in Lilongwe City and provides free specialty care. KCH is a national teaching hospital with 1,000 beds serving a catchment area of nearly 7 million people (81). Smaller, district-level hospitals, private facilities, and local health centers refer patients to KCH. Nurses, clinical officers, and medical assistants usually provide care at lower level facilities. Private pharmacies and dispensaries, where patients can purchase medications, are located throughout the district.

Study Sites

Recruitment and enrollment of study participants occurred at hospitals, clinics, and community neighborhoods in Lilongwe district. We recruited patients from the oncology clinic at KCH. Health care providers were recruited from KCH, Bwaila District Hospital, and Lighthouse Clinic in Lilongwe. Additional participants from the general population were recruited from various rural and urban TA areas in the district.

Study Population

This study included three population groups: breast cancer patients, health care providers, and community-based participants. The number of participants in all phases of the study, including those

participating in pilot testing was 285. All participants were required to be over 18 years of age and able and willing to review and provide informed consent to be included in the study. Additionally, certain participants had to meet the following inclusion criteria to participate in this study: for breast cancer patients, clinical presentation or pathological confirmation of breast cancer diagnosis; and for health care providers, formal employment at a hospital or health clinic in Lilongwe.

Research Design

This was a nonrandomized, non-interventional, observational study. We used two main data collection instruments throughout the course of the study, including qualitative interview guides (Appendix A) and a knowledge, behaviors, and preferences questionnaire (Appendix B). The interview guides were adapted for each study population (patients, providers, and community women). All data collection instruments were created in English and translated into Chichewa, the local language. Each participant was provided a small travel reimbursement or chitenje for their time and effort equivalent to approximately 5USD per UNC Project Malawi standards. At the end of each interview, the research team member reviewed a cancer fact sheet (Appendix C) with the participant.

Key Data Measures

Data were derived from two main sources: interviews transcripts, and survey responses. The main outcomes for each data source are outlined below:

From the in-depth interviews (Aim 1):

1. Qualitative responses from breast cancer patients regarding breast cancer experiences and reasons for delays to care

2. Qualitative responses from health care providers regarding barriers to early breast cancer detection and treatment management, and important factors affecting early detection services

3. Qualitative responses from women in the community on perceptions of breast cancer and early detection, and factors influencing preventive health seeking behaviors

From the cognitive testing interviews (Aim 2):

1. Acceptability of design and usability of tool in low-literacy population

2. Feasibility of administering preference assessment tool

From the survey (Aim 3):

1. Proportion of participants aware of breast cancer

    a. Knowledge of signs/symptoms of breast cancer

    b. Knowledge of risk factors of breast cancer

    c. Mean knowledge score

    d. Predictors of breast cancer knowledge

    e. Perceived threat of breast cancer

2. Proportion of participants aware of BSE

    a. Proportion of participants having ever performed a BSE

    b. Reported benefits of BSE

    c. Reported barriers of BSE

3. Proportion of participants aware of CBE

    a. Proportion of participants having received a CBE

    b. Reported benefits of CBE

    c. Reported barriers of CBE

4. Proportion of participants aware of cervical cancer

    a. Proportion of participants with knowledge of cervical cancer

    b. Predictors of cervical cancer knowledge

5. Proportion of participants aware of cervical cancer

    a. Proportion of participants having received cervical cancer screening

    b. Predictors of cervical cancer screening

6. Utility of breast cancer detection intervention attribute levels

7. Importance of breast cancer detection intervention attributes

Aim 1. Explore local factors that influence breast cancer beliefs and early detection behaviors through interviews with breast cancer patients, providers, and women from the community.

Overview and Rationale. The proposed aim allowed for a deeper understanding of cultural nuances and subtleties influencing breast cancer beliefs regarding early detection. It is important to understand how

the disease, detection strategies, and treatment are perceived by Malawians in order to address awareness and barriers to care. In-depth interviews are an effective way to gain insight into how people interpret their experiences, especially for sensitive topics like women's health. By interviewing patients, providers, and women in the community we obtained different views of socioeconomic, individual, interpersonal, and health system characteristics that influence breast cancer and early detection.

Conceptual Model. The goal of this aim was to investigate local beliefs and social contextual factors that influence Malawian women's perspectives about breast cancer as well as decisions to seek, delay, or access breast cancer detection and diagnosis strategies. In order to do this, we considered concepts from illness behavior theory, the help-seeking process, and the local cultural and social context of Malawi. According to Mechanic, "interactions between personal history, social situations and the opportunities and constraints of community institutions and social norms" are part of help-seeking behavior in response to identifying a symptom (82). We used the social contextual framework to guide the research of Aim 1 to understand the factors that may affect how women interpret and give meaning to breast cancer early detection. The application of the social contextual framework for cancer behavior displayed in Figure 3.2 focuses on multiple levels of factors that shape the day-to-day experiences of individuals (83). The complex relationships between social context, culture, and beliefs about health and cancer influence women's health-seeking behaviors, including early detection of breast cancer.

Figure 3.1. Application of the social contextual framework

According to this framework, socioeconomic factors such as marital status, education, employment, and health literacy shape social context and are strong determinants of breast health behaviors (83). These social categories can lead to differential exposure to resources, opportunities, and experiences which reflect social inequalities (84). In addition, this framework takes a social ecologic approach to conceptualize the social contextual modifiers and mediators allowing multiple levels of influence. For example, individual factors (e.g., competing health needs and material circumstances), interpersonal factors (e.g., social ties and family roles/responsibilities), health system factors (e.g., availability and affordability of care), and societal factors (e.g., discrimination) may influence breast care-seeking behaviors.

This conceptual framework also includes psychosocial factors and social contextual factors that mediate the relationship between demographic characteristics and health behavior. Psychosocial factors, such as beliefs and illness perceptions, build on concepts from behavior theories to explain their importance in determining health behavior. Social norms and relationships are also mediators of health behavior.

Underlying cultural factors may influence the social contextual factors as well as the psychosocial factors that predict health behavior. For example, illness/symptom disclosure, religious beliefs, social networks, and patient-provider relationships are often driven by culture and have been linked with breast cancer behavior. Importantly, cultural beliefs regarding women's roles can have a profound effect on women's health and health behaviors.

Given the lack of information on social contextual factors of breast cancer in Malawi and the importance of improving early detection, investigating local beliefs and health practices is crucial for developing effective cancer control interventions.

Design. We developed three semi-structured interview guides to solicit beliefs and perceptions of breast cancer from breast cancer patients, health workers, and women from the community (Appendix A). The open-ended, semi-structured guides were designed to encourage candid narration about preventive care, breast cancer, and treatment delays. Broad interview topics included women's perceptions of cancer, causes of cancer, potential to treat or cure breast cancer, health behaviors, locally available screening services (e.g., VIA screening for cervical cancer), and other cultural norms and values. Probing questions were used as needed to encourage additional thoughts if sensitive or supporting topics were not mentioned.

Sample Size. We recruited 20 breast cancer patients, 10 health care providers, and 20 women from the community for the interviews. As an exploratory public health study, this number was based on recommended numbers for qualitative studies and the maximum number that can be reasonably enrolled based on budget and expected attendance at the clinic site. Qualitative research methods generally suggest that 15-30 interviews are an appropriate sample size to provide reasonably representative responses of a group, and these sample sizes are typical of many similar studies taken from the medical literature.

Recruitment. Breast cancer patients were recruited from KCH oncology clinic. A review of the clinic registry supplemented local staff members' identification of patients who were diagnosed with or treated for breast cancer. We purposefully recruited patients who were recently diagnosed, currently undergoing treatment, and under more long-term surveillance. Following their clinic visit, a study team member approached patients individually and invited them to participate in an interview. Once a patient consented

and enrolled in the study, she was interviewed immediately or at a time agreed on by the patient and the study team member.

Health care providers who were involved in routine clinical care for women were recruited from the three health care facility study sites. The health workers, including midwives, nurses, clinical officers, and consultants, were selected purposefully based on their involvement in women's care or cancer treatment. The principal investigator (PI) approached providers individually and worked with each provider to find a convenient time and private location to consent the provider and conduct the interview.

For community-based participants, we identified purposefully selected TA areas to recruit women from rural and urban neighborhoods. The study team visited the area before the interviews to meet with the local chief or village headman and brief them on the study and get permission to conduct interviews. We recruited four random participants from different areas and attempted to include participants from across the entire geographic boundaries of the TA area. Once recruited, the interviewer worked with the participant to find a private location in the participant's home to obtain informed consent and conduct the interview.

Data Collection. Participants were recorded providing oral informed consent prior to asking any questions in addition to written signed consent. Per UNC Project protocol, illiterate participants were asked to provide a thumbprint and have a third party witness sign on their behalf.

Each participant responded to demographic questions. For the patients, we attempted to collect clinical data on stage, diagnosis date, hormone receptor status, and treatment type for the breast cancer patients from the patient health passport (medical record). For providers, we also collected data on their training, and work experience.

All interviews with health care providers were conducted by the PI in English, however, the rest of the interviews were conducted in Chichewa by two local interviewers. All interviews were digitally recorded and additional field notes were taken to document participants' behaviors or non-verbal reactions to questions. Jottings taken during all research encounters were systematically developed into interview summaries and a growing body of detailed fieldnotes.

Analysis. All interviews were transcribed verbatim and those conducted in Chichewa were translated into English. Back-translations were be performed on random three-page segments to check for accuracy. We

used qualitative data software ATLAS.ti (Atlas.ti Scientific Software Development, Berlin, Germany) to systematically organize and analyze transcribed interviews. We read transcripts to create a document summary of each interview, highlighting important quotes and initial impressions of the participants' views on breast cancer. We also analyzed preliminary results throughout the fieldwork to allow emergent themes to be incorporated into data collection for the remaining interviews.

We analyzed patient transcripts separately from provider and community transcripts. The focus of the analysis of patient interview data was to explore these narratives to identify cultural beliefs, values, norms, and day-to-day experiences that may explain Malawian women's perceptions of preventive care, breast cancer, and reasons for delay. Patient transcripts were read repeatedly by two experienced coders to identify major concepts and themes. Textual units representing thoughts and experiences were coded and grouped according to major themes and concepts within themes. We organized the codebook using the conceptual framework (see Figure 3.1) and any additional categories not originally identified in the conceptual model were added to the codebook as necessary. Through this iterative process, codes were redefined and new themes were identified through consensus between the two coders. The final codebook was independently applied by both coders. We examined co-occurrences and frequencies of codes used to determine common themes. We compared code frequencies across and within participants' demographic characteristics to look for patterns among participant subgroups (e.g., education and rural residence). Additionally, we examined connections and relationships between co-reported perceptions (e.g., whether women report lack of awareness and seek care from traditional healers).

For the provider and community interviews, we used a similar analytic approach, with a focus on identifying perceptions of preventive care, breast health, early detection, and factors influencing preventive care use to help inform the attributes and levels used in the preference assessment tool (Aim 2).

Aim 2. Develop a preference assessment tool to elicit Malawian women's preferences related to breast cancer services.

Overview and Rationale. Patient preferences are essential to understand the extent to which women value attributes of breast cancer early detection and cancer prevention services. A variety of quantitative and qualitative techniques exist to elicit preferences, including DCE, best-worst scaling (BWS) exercises, and close-ended questionnaires (85). Conjoint analysis has previously been applied to estimate preferences for mammography (86, 87), BSE instruction (88), and a range of other health interventions (89). Findings from conjoint analysis uncover how women value selected attributes of cancer early detection services by asking them to state their choice over different hypothetical alternatives (90). Understanding preferences regarding health service options helps explain individual and aggregate choice behavior and allows future predictions of responses to new service delivery opportunities. For this aim, we developed a DCE to elicit and identify preferences for future early detection interventions based on a review of the literature and results from the provider and community interviews conducted in Aim 1. We conducted cognitive interviews with eight women to ensure it was cognitively feasible; we also tested a BWS exercise to determine which design was more appropriate for the target population.

Conceptual Model. Variation in health-seeking behavior and health care utilization highlight the importance of understanding what women want in regards to cancer detection services. Conjoint analysis is a stated preference method that involves presenting respondents with different scenarios and asking them to choose between them (90). By forcing women to state which hypothetical situation they would prefer, their choices reveal preferences about a given option. This approach combines economic utility theory and psychological experimental design; thus stated preference DCEs provide deeper understanding of health consumers' intended behavior (91).

DCEs provide information not just on what is important to women, but also on the strength of preference for given services and trade-offs between service attributes. This technique is rooted in Lancaster's theory of value and consumer choice, which states that a good or service can be decomposed into separate attributes, and the total utility gained from using a service is a function of the individual utilities of the attributes of the service (89, 92).

Random utility theory posits that a consumer's utility (U) for a choice is latent quantity that can be modeled from a behavioral response comprising both explainable (V) and random unobservable (ε) components for individual *n* and option *i* (90).

$$U_{in} = V_{in} + \varepsilon$$

$$U_{in} = V_{in} + \varepsilon$$

V_{in} is the indirect utility function, and can be characterized as

$$V_{in} = \alpha + \beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_k X_k$$

$$V_{in} = \alpha + \beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_k X_k$$

where V is the utility or benefit of an alternative, α is the alternative specific constant, X is the attribute, and β is the coefficient estimate of each attribute (93). As respondents choose between different health service options, it is assumed that they are considering all the attributes and making trade-offs between them, selecting the option with the highest utility. This application of random utility theory allows us to estimate the importance of each attribute (utility) and the trade-offs between attributes.

Each individual's decision is based on complex interactions between her perceptions of early detection, her awareness of cancer, how able and willing she is to make a decision to seek early detection, and the attributes of the health service (86). Because no studies have explored breast cancer preferences in Africa, it was unclear which attributes of cancer detection services Malawian women value the most. However, understanding women's motivations can contribute to designing interventions to promote early detection that meet women's preferences and are more likely to be accepted. By developing a relevant tool to understand women's intended early detection and screening behavior, we can identify and investigate potential ways to improve cancer detection services.

Design. We followed the International Society of Pharmacoeconomics and Outcomes Research guidelines to develop the preference tool (85). We selected attributes (characteristics) of cancer early detection services, assigned levels to each attribute, identified plausible hypothetical scenarios to present, and conducted cognitive interviews to test the tool. It is imperative to identify relevant attributes that are amenable to change and to include plausible ranges (85); therefore, we relied on a review of the literature and qualitative data from Aim 1 to identify important attributes and appropriate ranges of levels.

Based on existing breast cancer decision-making literature and other DCE conducted in SSA, we established an initial set of potential attributes and levels. We anticipated having five attributes with no more than five levels to avoid a complex design. We amended the list after reviewing the health worker and community interview transcripts and selected the most relevant attributes and plausible levels for inclusion in the DCE. The final attributes and levels included in the DCE are displayed in Table 3.1.

Table 3.1. Attributes and levels used in final discrete choice experiment

Attributes	Levels
Travel time	
	<1 hour by foot
	1-2 hours by foot
	>2 hours by foot
Health encounter where intervention is available	Health talk in facility waiting area
	Community health gathering Cervical cancer screening
	Family planning clinic
	Child under 5 clinic
Health worker	
	Doctor
	Health surveillance assistant
Gender of health worker	
	Male
	Female
Early detection strategy	
	Breast health awareness
	Clinical breast exam
	Breast health awareness and clinical breast exam

We used Sawtooth Software (Sequim, Washington) to create a main effects fractional factorial design to have a reasonable number of choice profiles and reduce respondent burden. We also designed the experiment to be balanced with minimal overlap. The choice profiles had images as well as written text to improve comprehension (94, 95).

Sample Size. We purposefully recruited eight low-income and/or low-literacy women to participate in cognitive interviews of the preference tool.

Recruitment. UNC Project Community Department staff and community advisory board leaders helped identify women from various areas in Lilongwe to participate in the cognitive interviews.

Data Collection. The trained interviewers conducted and digitally recorded the cognitive interviews at UNC Project. Cognitive interviewing is a commonly used method for pre-testing survey questions, which

combines psychology and survey methods to help identify problematic questions or tasks in data collection instruments. This involved asking survey respondents to think out loud as they went through the questionnaire and to share what they were thinking as they processed questions and chose answers.

The interview included practice questions and choice sets followed by probe questions designed to determine: 1) whether choice sets were administered with relative ease; 2) how choice sets were interpreted by respondents; and 3) the factors considered by respondents when deciding between choices. Follow-up probing questions were used to gain insight into how the respondent reached their answer. Responses and explanations were recorded on paper by the interviewer. Respondents were also be asked about how they would prefer to learn about the attributes. For example, the distance to the facility attribute could have been provided as a number (e.g., the facility is 10 kilometers away) or descriptively (e.g., short travel time or long travel time). At the end of the interview, the interviewer and PI had a debriefing meeting and summarized the problems highlighting problematic words or questions.

Analysis. We reviewed the responses to the follow-up probes to determine which attributes and levels were difficult to understand. We also reviewed the debriefing summaries and results of the cognitive interviews and revised the experiment to ensure wording and images used were clear, unambiguous, and permitted respondents to successfully understand the choice options. We conducted a comparative analysis to determine error and interpretation patterns, focusing on whether respondents understood the definitions of attributes and levels and whether they understand the choice tasks.

Aim 3. Administer a questionnaire to assess women's current knowledge, beliefs, behaviors, and preferences related to breast cancer and early detection services

Overview and Rationale. Quantitative data collected from surveys allow us to gather non-experimental data to statistically analyze broad population patterns of variations. Although previous research has explored knowledge of cervical cancer in Malawi, no studies have examined breast cancer knowledge and early detection behaviors. This survey component of the study included a random sample of households in Lilongwe district to ensure urban and rural residents were adequately represented. This design provided a breadth of data regarding current knowledge among Malawi women and highlighted knowledge gaps in need of educational programming.

Conceptual Model. The Health Belief Model (HBM) is often used to guide cancer screening programs and evaluations to understand participant perceptions and behaviors (96), thus the HBM served as the conceptual framework for the development of the questionnaire in this aim. The HBM was selected because it has been used to help explain and predict factors that influence individual's health behaviors related to cancer services.

The HBM posits that multiple factors influence the adoption of health behaviors including 1) *perceived susceptibility*, or perceived risk of a health condition; 2) *perceived severity* or seriousness of harm; 3) *perceived benefits* or positive aspects of a health action; 4) *perceived barriers*, things that may be inconvenient, painful, or expensive; 5) *cues to action* that motivate the health action; 6) *self-efficacy*, or confidence (97). The combination of perceived susceptibility and severity is displayed as perceived threat in Figure 3.2. Additionally, people would not be expected to accept a health behavior unless they perceive the benefits outweigh the barriers.

Figure 3.2. Application of Health Belief Model for early detection

For example, whether a woman believes she is susceptible to a particular health problem (e.g., breast cancer), perceives this problem as serious, or is convinced that there is benefit in undertaking a preventive measure (e.g., seeking help or attending screening) may all influence her behavior. According to the HBM, the more women understand the danger of breast cancer, the more likely they will be willing

to modify their behavior to take action to reduce their risk. However, Malawian women may have different beliefs about the cause of cancer, which could affect perceived susceptibility. Additionally, a woman must feel threatened by her current behavior, believe that early detection will be beneficial, and feel confident enough to overcome potential barriers. Different barriers may be more important for certain groups of women, such as modesty among Muslim women and costs for women with lower incomes.

Other demographic characteristics may also influence beliefs and indirectly influence health behaviors. Two of the key factors driving an individual's beliefs are education and knowledge of the disease; women must be able to recognize symptoms of breast cancer in order to seek medical care at a health care facility – they need to be "breast aware." Cues to action, such as recommendations from health care providers, are other modifying factors that can affect women's health behaviors.

Design. The questionnaire was designed to determine breast cancer knowledge, risk perception, and current early detection behaviors. The Champion scales are commonly used to assess the HBM constructs relevant to breast cancer detection have been translated into other languages and tested among numerous ethnic groups (98, 99); however, the scales have not been widely tested in Africa nor do they measure CBE perceptions. Therefore, we adapted questions from other scales and knowledge surveys from prior studies of mammography and BSE (5, 6, 100, 101). The questionnaire was created in English and translated into Chichewa. The questionnaire was also reviewed by a Malawian medical officer and a physician who currently work in reproductive health and oncology clinics and revised accordingly. The main domains included in the questionnaire are outlined in Table 3.2.

Table 3.2. Survey measures

Domain	Measures
Socio-demographic characteristics	Age, tribe, residence, religion, marital status, educational status, occupation, electricity, running water, roof type
Health and health behaviors	HIV status, personal cancer history, physical health, quality of life, smoking status, alcohol consumption, reproductive history (parity, age of first pregnancy, menopausal status, contraceptive methods, breastfeeding history), recent physical exam
Cancer awareness	Personal cancer experience (family history or peer-related experience)
Breast cancer knowledge	Awareness of breast cancer Awareness of BSE, CBE Knowledge of risk factors, signs & symptoms, treatment options
Health beliefs	Perceived threat of breast cancer Benefits of BSE, CBE Barriers to BSE, CBE Fear of breast cancer Fatalistic beliefs
Practices	History of BSE, CBE Willingness to participate or adopt early detection behaviors
Cervical cancer	Awareness of cervical cancer, HPV Awareness of VIA Knowledge of causes, risk factors, signs & symptoms Screening history Acceptability of screening
Preferences	See Aim 2

Notes: BSE, breast self-exam; CBE, clinical breast exam; HPV, human papillomavirus; VIA, visual inspection with acetic acid

During the early phases of the dissertation research (Aims 1 and 2), we determined that breast cancer awareness would likely be low, therefore we also included questions about cervical cancer, which is more common in Malawi. Numerous studies have shown cervical and breast cancer behaviors to be positively correlated, and often indicative of utilization. This section was also added because many experts recommended a comprehensive women's health exam to include screening for both types of cancer.

The questionnaire was administered by trained fieldworkers on handheld tablet computers using the Open Data Kit Collect application. Paper copies were also available for hand-written completion in the

case of tablet malfunction or participant preference. The DCE exercise was administered on full-size paper and displayed in a flipbook. Responses were input directly into the tablet.

Sample Size. The questionnaire was pilot tested with 4 women attending KCH clinics and 8 women in two rural villages and revised slightly to adjust for skip patterns.

For the final administration of the survey, we recruited 213 participants to complete the combined knowledge questionnaire with DCE exercise. We use the response rate of the breast cancer knowledge questionnaire to provide the statistical justification of the study. Data from studies in other African countries suggest that the response rate is on average 84%, so a large proportion of women approached are willing and able to complete breast cancer questionnaires. To calculate a 95% confidence interval for the averaged proportion with a 5% margin of error, we need a sample size of 207.

Recruitment. We identified households from a random sample of geographic coordinates from residential TA areas within Lilongwe district. We included rural and urban TA areas. Consistent with previous UNC Project studies, we used global positioning system (GPS) devices to identify households closest to the selected coordinate. Fieldworkers approached the home and assessed eligibility as described above.

Once recruited, the study coordinator worked with the participant to find a private location in the participant's home to conduct the study interview. Once in the private location, the study coordinator obtained informed consent and began the interview.

Data Collection. The trained fieldworkers administered the survey, reading questions aloud to participants with specific examples or probes to help clarify questions. This interview-administered survey capitalized on in-person access to the participant and minimized the risk of non-response. Respondents were randomly allocated to one of 12 versions of the DCE exercises.

Responses were uploaded to Open Data Kit each day after returning from the field and were automatically generated in a secure database.

Analysis. Basic descriptive statistics were calculated for the questionnaire participants using Stata 13. Frequencies for the categorical variables and means/standard deviations for the continuous variables were analyzed.

We created scores from the survey for knowledge of breast cancer, including risk factors, signs/symptoms, detection methods, and treatment as shown in Table 3.3; we created similar scores for

cervical cancer and cervical cancer screening (results in Appendix D). For the knowledge measures, each

respondent was scored based on the number of correct responses.

Table 3.3. Breast cancer knowledge scoring from survey measures

Outcome Measure	Survey Question	Response Scoring	Total Possible Score
Signs and symptoms knowledge	Please tell me if you think the following things could be signs of breast cancer (bloody discharge from nipple, breast lump, breast pain, itchy nipple, discoloration of nipple, breast skin retraction, discoloration of breast, change in shape of breast, skin dimpling).	1 point per correct sign	9
Risk factor knowledge	Please tell me if you think the following may increase the chance of getting breast cancer (genetic and family history, not having children, first delivery after 30 years, short duration of breast feeding, getting older, being overweight, fatty diet, drinking alcohol).	1 point per correct risk factor	8
Treatment knowledge	Please tell me if you think the following options can treat breast cancer (surgery, herbal medicine, chemotherapy, hormonal therapy)	1 point per correct treatment	3
Total breast cancer knowledge			20

Analyses were conducted on a pooled dataset of women including both rural and urban samples.

We assessed correlations between demographic characteristics and knowledge of breast cancer, breast

cancer detection methods, and current behaviors. Logistic regression models assessed the significant

predictors of cancer awareness. Additional analyses included examining the relationship between

knowledge of cancer and early detection practices.

The responses of the DCE were analyzed in Sawtooth Software using the hierarchical Bayesian

module for conjoint analysis (102, 103). We estimated statistically significant differences in choices, the

importance of different attributes given the range of levels, and the utilities of each level of the attributes.

Ethical Approval

  This observational study was reviewed and approved by the University of North Carolina at Chapel Hill Non-Biomedical Institutional Review Board (study #13-2926). The aims were approved by the Malawian National Health Service Research Committee (protocol #1309).

CHAPTER 4: A FRAMEWORK FOR IMPROVING EARLY DETECTION OF BREAST CANCER IN SUB-SAHARAN AFRICA

Introduction

Breast cancer is the most common cancer in Africa, and the leading cause of cancer death; the mortality to incidence ratio of breast cancer in Africa is 47% (1). Women are generally diagnosed with advanced disease due to low awareness and lack of screening and diagnostic services (34). Early detection and timely treatment are essential to improve survival; therefore, understanding barriers and facilitators of early detection and treatment initiation may help identify where meaningful public health interventions are needed and how they could address delays to cancer care.

Because an individual's beliefs and knowledge about cancer play a critical role in health behavior, exploring psychosocial factors that influence behavior is important (96). Women's lived experiences, social networks, and socioeconomic circumstances may also influence knowledge, decisions, and ability to access health care (83). This suggests that how women interpret and give meaning to breast cancer symptoms, as well as broader social and contextual influences may affect help-seeking behaviors.

Systematic reviews of quantitative and qualitative breast cancer delay studies have identified risk factors for delay and found that delays of three months affect survival (58, 104-106). For example, low socioeconomic position, lack of cancer knowledge, embarrassment of being examined, distance to the health facility, and quality of care may directly or indirectly lead to varying lengths of delay in care (59, 63). However, few studies from Africa, where health resources are scarce and cancer awareness is low, have been conducted or included in such reviews. In addition, a majority of previous qualitative studies are descriptive, and few develop conceptual models or theory to understand the complex factors influencing delayed and early detection (60, 63, 107). Indeed, few delay models have explored the influence of alternative treatment and traditional medicine, which is commonly used among cancer patients across Africa (108). To our knowledge this is the first conceptual model providing a

comprehensive picture of breast cancer help-seeking behaviors, delays, and access to care issues developed from empirical evidence from sub-Saharan Africa (SSA).

The objective of this study was to explore how Malawian women were diagnosed with breast cancer and what influenced their decisions and ability to access breast cancer care. This paper proposes a framework to understand delay and improve early detection and treatment initiation in SSA, grounded in findings from in-depth patient interviews. We present a framework based on patient decisions and interactions with their social network and health system, and how these interactions influence patient behaviors and the ability to access and receive diagnostic and treatment services. We describe potential breakdowns at specific stages and transitions between stages and how different factors can cause delays along the breast cancer help-seeking pathway.

Methods

Study setting

The study was conducted in Lilongwe, the capital of Malawi, as part of a larger project investigating breast cancer knowledge and preferences. Malawi is a small, but densely populated country in south eastern Africa. A majority of the population lives in rural areas and relies on subsistence farming for income (68). The public health care system provides free basic services through local health centers, district hospitals, and central referral hospitals. Although the country faces a significant HIV burden, with 12% of the adult population being infected, non-communicable diseases like cancer are increasingly important public health problems (64, 73, 109).

Study design

We conducted in-depth interviews with patients because qualitative methods are well-suited for exploring how people give meaning to their lived experiences and circumstances (110), and tend to provide comprehensive data about how people interpret and act on symptoms while taking into consideration the social and cultural context. The sample consisted of 20 breast cancer patients receiving care at Kamuzu Central Hospital, one of two national teaching hospitals in Malawi where breast cancer treatment is available. Local fieldworkers worked with oncology clinic staff to identify and recruit eligible patients with a confirmed pathologic diagnosis of breast cancer. To ensure that a range of perspectives

were incorporated, individual interviews were conducted with patients of varying age, residence, and phase of treatment using purposive sampling.

Data collection

In-depth interviews were conducted between April 2014 and August 2014. We developed a semi-structured interview guide based on existing literature regarding health-seeking behaviors, explanatory models of illness (111), and breast cancer knowledge and beliefs, but allowed topics to evolve with the themes emerging from the interviews. The fieldworkers and principal investigator met regularly to discuss the responses, and the interview guide was revised to provide more comprehensive insight into emerging topics. Broad topics included health-seeking behaviors, cultural beliefs about cancer, breast cancer knowledge, treatment experiences and delays, and demographic characteristics.

All interviews were conducted in the local language, Chichewa, and recorded digitally, then transcribed verbatim and translated into English for analysis. Translated grammatical errors were corrected to ease readability as necessary while still preserving the cultural significance of the content. Translation consultations occurred regularly to discuss the use and meaning of problematic words. In addition, multiple pages of four interview transcripts were randomly selected for back translation to ensure conceptual accuracy and that the meanings of the transcripts were not lost (112, 113).

Data analysis

We organized and analyzed the transcripts using Atlas.ti 7 (Atlas.ti Scientific Software Development, Berlin, Germany). In the initial coding phase, an inductive approach was used to identify themes emerging from the transcripts. The original codebook was organized around the social contextual model (83) and the data collection team's preliminary interpretation of participants' responses. A second coder also read the transcripts multiple times to identify any other recurring issues related to breast cancer diagnosis and care not already in the codebook. Through this iterative approach to data analysis, the two coders discussed themes emerging from the data to redefine existing codes and added new codes to help capture the patients' experiences more appropriately. Both coders independently reviewed transcripts using a common codebook and discussed divergent applications of codes, revising the definition and examples until consensus was reached. For the final phase of coding, the revised codebook was applied to all transcripts. Code frequencies and co-occurrences were used to identify

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super codes and overarching themes in addition to using Strauss and Corbin's paradigm approach to organize and conceptualize the conditions, actions/interactions, and consequences within the transcripts (110). We diagrammed and wrote storylines of the various trajectories women narrated in order to construct a conceptual framework representing breast cancer help-seeking patterns affecting diagnosis and treatment.

We built upon Andersen and Cacioppo's model of delay by combining aspects of self-regulation theory, the theory of reasoned action, and the Precaution Adoption Process Model (PAPM) (97, 114, 115). Andersen's model of total delay outlines various stages of perceiving, interpreting, and responding to symptoms. The final two phases of delay in the model include scheduling and treatment delays, which are inherently different in limited-resource settings like Malawi, and were not applicable in our framework. The theory of reasoned action and PAPM identify cognitive stages of decisions to take action (116, 117). Additionally, the PAPM emphasizes that people who are unaware of a health issue face different barriers than those who know and decide not to act, which is well-suited for our setting because breast cancer is a growing public health problem in SSA, yet awareness is generally low. Finally, we situated our framework within the social ecological model to explain how breast cancer help-seeking behaviors and access to care are influenced at the individual, interpersonal, health care provider and system levels (118).

Results

We recruited 20 patients with varied levels of education, employment status, age, and residence as presented in Table 4.1. Women were at different phases of cancer care, including recently diagnosed but not yet receiving treatment, receiving neoadjuvant chemotherapy before surgery, on adjuvant chemotherapy post-mastectomy, receiving palliative care for metastatic disease, and under surveillance care. The median age was 47 and more than half (11) of patients were younger than 50 years old at the time of the interview. Eight of the patients were from Lilongwe; the rest traveled from outside the district to receive care at the central hospital. The majority of women were Christian and 75% were married. Many women had limited education: five had no formal schooling, and eight had attended some primary school. In terms of economic status, only eight women reported having a regular source of income and five women had electricity in their homes. The demographic characteristics of this sample were similar to the

most recent Demographic and Health Survey data (86% of women are Christians, 15% have no formal education, and 9% of households have access to electricity).

All women were symptomatic when they were diagnosed; none were detected through screening as these services remain nearly absent in Malawi. Women's narratives illustrated a complex set of conditions, beliefs, decisions, and actions that influenced their cancer help-seeking behaviors. Most participants experienced long delays between symptom onset, diagnosis, and treatment initiation ranging from a few weeks to a few years. Although patients discussed many issues related to their cancer experiences, this analysis focused on factors affecting diagnosis and entry into cancer care.

The framework

Figure 4.1 depicts the steps along the pathway to breast cancer diagnosis and treatment initiation in Malawi. The framework comprises 6 stages that emerged as important themes in patient interviews, including: 1) notice and interpret the initial symptom, 2) monitor changes and infer illness, 3) decide to seek help, 4) intend to seek help, 5) reach the health care facility, including the initial local facility and also referral facility, and 6) receive appropriate care. This patient's description exemplifies this process:

> "At first, [the] top of the breast, became very hard. But it was not painful. So I was just saying, maybe that is what happens after menopause. But the other one [breast] was ok. I stayed like that for a year. But still I was not feeling well no matter how much medication I took. Then I noticed that the breast had started swelling. That was when I asked my friends, 'Look at my breast, is this what happens after menopause?' The lump confused me…the breast felt hot at times, but most of the time it was not painful…so I was confused. People said, 'Go to the hospital. This may be cancer…my husband's niece had the same symptoms. She was late. She died. When a person is diagnosed early, she gets cured. So go.' That was how I started going to the hospital."

The pathway is displayed here with sequential stages, but in reality it is a complex decision-making process. Depending on their circumstances women described different trajectories such as moving quickly, getting stuck, skipping steps, or looping back to earlier stages. For example, a woman may never move beyond the stage of inferring illness, or she may have a prolonged interval there before eventually moving through the remaining stages. Thus, as described previously, early detection depends

on the decisions and interactions of patients and other social and environmental factors, but in SSA these processes are complicated by a context of extreme poverty, cultural beliefs and practices, and an overburdened health care system. We describe several themes that emerged as factors affecting each stage below, in italics (Table 4.2).

Stage 1: Notice and interpret the initial symptom

None of the women interviewed were diagnosed asymptomatically; therefore, action in the absence of symptoms was essentially nonexistent. Given the local conditions and lack of screening services, the first stage is that a woman discovers "something strange" on her breast. As many health theories suggest, a woman's knowledge, beliefs, and risk perceptions influence how she interprets the symptoms she experiences (114, 115). Patients rely on previous memories and experiences as they process the changes happening in their body (119). However most of participants in this study did not have preconceived ideas of what a breast cancer sign was. As a majority of the patients did not consider their symptom to be very serious, the delay from their initial interpretation of the symptom to seeking help was due to a lack of perceived illness. For them, it was more of a non-threatening problem, which caused some women to dismiss the change, thinking it was a trivial ailment. When they were unsure of what it was, they delayed seeking treatment for several months while waiting for it to "go away," which was common a woman did not "feel sick."

Stage 2: Monitor changes and infer illness

During Stage 2, women may monitor symptom development and reappraise changes over time before attributing causality to their symptom. Women in this study spent a few weeks to a few years experiencing persistent symptoms before seeking help. Andersen and others claim that attributing symptoms to cancer is determined first by knowledge of possible cancer symptoms and second by evaluation of one's own symptoms as a well-known or uncommon indicator of the disease (59, 114). Because of their lack of awareness, most of the participants did not initially attribute their symptoms to cancer. Instead they attributed the strange and unfamiliar changes on their body to other causes, such as pre-existing conditions, aging, trauma, or common ailments, leading to long delays. For example, three women were pregnant when they first experienced symptoms and attributed their symptoms to the pregnancy, leading them to delay seeking medical care until after delivering the baby. As Ruth explained,

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"I just saw the breast changing. It was changing but it was not painful. Because I was pregnant, I just thought it was because of that." Other women misinterpreted their symptoms as swelling from clogged milk or from having difficulty breastfeeding. Other participants with unfamiliar symptoms self-diagnosed them as a different condition (e.g., boil or rheumatism). Though many participants began considering other possible diagnoses at this point, most were not worried because they did not perceive their symptom to be a serious problem.

Knowledge and risk perception

A few women who were aware of breast cancer did attribute their symptoms to the disease. Although these women had sufficient knowledge to recognize something was wrong, some delayed taking action because they were in denial about their symptoms. Eliza described, "You just say, 'Ah, you are okay' while you have a problem…So you realize at a later stage when you see a strange thing in your body." Ignoring symptoms is a common coping response to suspecting symptoms may be indicative of cancer (115, 120). Conversely, some women who were previously aware of breast cancer or had prior peer-related cancer experiences sought help sooner. For example, two women worked in the health system as a nurse and health surveillance assistant (HSA), and their health education from their occupation helped them to act quickly when they noticed the symptoms; they went straight to the health facility to get diagnosed.

Stage 3: Decide to seek help

The transition from symptom monitoring to seeking help is a crucial stage on the help-seeking pathway. Though some women's interpretation of symptoms based on pre-existing knowledge and beliefs, may be enough to motivate them to seek medical care, other women may need additional cues to seeking help. Interviews revealed three emergent themes around the decision to seek help: the nature of escalating symptoms, attitudes about the benefits of medical interventions, and experience of peers with cancer-related experiences. Additionally, beliefs about traditional healing intervened and altered the path for some women as they decided to seek help from lay people. The timing of this step is critical because as women wait and symptoms progress with noticeable changes, the disease also becomes more advanced, affecting survival (58).

Nature of the symptom - seeing is believing

Women often experienced multiple symptoms for many months, and the nature of the symptom made a difference in health-seeking behaviors. Delay was especially common when women did not experience pain. Even women who were aware of breast cancer struggled to interpret the signs and decide to get help, as Promise explained, "It felt hard when I touched it…the breast was not painful…and it was difficult for me to notice that it was cancer because the breast was ok. It wasn't painful."

However, once their symptoms progressed (e.g., the lump grew or an additional lump formed) women decided to seek help. Self-regulation theory is helpful to understand and explain how women interpret their symptoms, re-evaluate threats based on changes, and respond with coping mechanisms (115). In our study, increased pain, bloody discharge, and the wound bursting were frequently mentioned as the change that triggered women's perception of seriousness of the symptoms. Experiencing visible symptoms, not just feeling a lump, but seeing it change, was a deciding factor for women to seek help. As symptoms escalated and became more severe, the disease threat led to fear, often prompting women to consult their social networks or changing their intention to seek medical care.

Attitudes toward medical interventions and trust in providers

Most women had positive attitudes about medical interventions and were pragmatic about breast cancer treatment; they trusted that the doctors would give them the "right medication" to "get rid of the problem." Although the majority of participants did not know what treatment options were available prior to diagnosis, they generally believed medical interventions available at the hospital were helpful and effective ways to get cured. Despite these attitudes towards the benefits of treatment, social norms about waiting to seek medical care until one is very ill, and not wasting providers' time made some women hesitate before acting on their decision to seek treatment at the hospital. In addition, many women held paternalistic views towards providers, commonly saying things like "only health workers can tell you if it's just a lump or if you need treatment" and "anything that the doctor tells me, I will accept." Most women who had never before heard of breast cancer were not afraid or worried about consequences of treatment. Although the attitudes may have helped them decide to seek medical care, it also affected their care at lower-level health centers when they were misdiagnosed. The patients rarely questioned the provider's knowledge and diagnosis, which in some cases led to delayed referrals.

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Cancer-related experiences among peers

Some patients knew someone who had been diagnosed with cancer previously, or had seen a woman in the village with only one breast. These women were more likely to act on that knowledge, speeding their decision to seek help. For some, the experiences and memories helped women recognize their symptoms, and for others, it triggered their decision to seek medical care. Seeing a woman with one breast also made women realize that surgery to remove the "sick breast" was an option and proved that women lived through the treatment. Additionally, while disclosing their symptoms to their family members and neighbors, people often relayed stories about others they knew who had cancer, prompting women to seek medical care.

Stage 4: Intend to seek help

Some women decided to seek help but did not immediately act on that decision or were unable to act on the decision. The theory of reasoned action suggests that behavioral intention is the most important determinant of behavior, and is influenced by attitudes and beliefs about a behavior (97, 117). In addition, some women went to their social networks or tried traditional remedies, which had positive and negative influences on the timing of their diagnosis.

Seeking help from social network

Most patients disclosed their symptoms to a family member, neighbor, or friend to get information, help interpret the confusing symptom, and determine the need for medical care. Husbands were generally the first person a woman told about her symptoms, but most also consulted their peers or elders in their villages. Patients' behaviors were strongly influenced by members of their social network and this was a common cue to action. Although women's narratives described how their interactions with mothers, daughters, and friends often encouraged them to "rush to the hospital" to find out what was wrong, sometimes seeking help from their social networks caused additional delays in care such as trying traditional medicine. For other women, their peers provided wrong information, reinforced their misconceptions, or suggested alternative explanations for their symptoms, which negatively affected them getting to the hospital for a diagnostic evaluation.

Seeking help through traditional remedies

Many women were confused about what caused their symptoms, and they did not understand why the changes happened, motivating some to try local and traditional remedies. Six women disclosed that they sought traditional medicine for their breast problem. Although most of them had no or very little primary education, four women who were aware of breast cancer still tried local remedies and consulted traditional healers based on their own beliefs about treatment efficacy or at the encouragement of their social network. The duration and types of traditional remedies used by patients varied, and they usually sought medical care after trying "many things to remove lumps, but [they] fail[ed]". For example, one woman went to a spiritualist in the village for four months before deciding to go to the hospital because she saw no change. Many participants also spoke anecdotally about other breast cancer patients they knew from the oncology clinic who went to herbalists before going to the hospital; they described how some women had many "tattoos" (cuts and scars) on their breasts from trying traditional herbs because they were "told that they were bewitched…that the lump was diabolic…magic." Traditional medicine caused delays before seeking medical care, but also when women were in between referrals, after chemotherapy, and after surgery. For example, one patient's family thought she was bewitched and that the surgery was not enough to heal her, so after her mastectomy they brought her to a witchdoctor where she took local herbs despite claiming she did not believe herbal remedies.

Seeking medical care

Throughout the interviews women spoke about two concepts that instilled a sense of responsibility to be tested and urgency to get treated early. Indeed many women discussed the importance of testing to know about one's health status and how rushing to the hospital and getting treatment early was beneficial. Although many women intended to seek medical care, they were not able to act on their decision because of economic hardships, roles and responsibilities, and structural barriers. Though participants expressed positive attitudes towards medical care and social norms supported seeking medical treatment, they were not always capable of following through on their intentions.

Importance of testing – "knowing how your body is"

Many women discussed how in general it is "good to know about your body" and that "you should be aware of your [health] status". They valued knowing whether or not they were sick and knew they could only be tested at the hospital, which motivated some to seek medical care. Women talked about

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screening and diagnostic testing without differentiating between the two; to them, getting tested was modeling a positive, perhaps even a preventive behavior, though in reality, they were diagnosed late. Nevertheless, many women talked positively of going to get checked for cancer.

Although some participants were told that they had cancer at lower level health facilities, most women indicated that they were diagnosed at the central referral hospital – where the biopsy was performed. This distinction was common; the confirmation test and getting the results were highly valued so a patient can "know what's wrong" and "get the real truth." In general women had positive views about testing and diagnosis because it meant they could "get help" and receive the "right treatment." Despite their attitudes about getting a confirmed cancer diagnosis, only four women were knowledgeable about breast self-exams; these same four women had also been screened for cervical cancer.

"Rush to the hospital" and early treatment benefits

Women shared the belief that the doctors at the hospital could help them and that treatments were effective, but they did not comprehend the effect of time on their health. Though many women described waiting for months while monitoring symptoms, they still believed they came quickly to the hospital after realizing the seriousness of their condition and heeding warnings from peers not to "just stay at home and do nothing. Rush to the hospital." As they reflected on their experiences, a few women questioned whether or not they had sought treatment late. Participants felt they sought help as soon as their symptoms escalated or after their families and friends told them to go. Once women decided to seek medical care, they wanted to go quickly, but they were not able to mainly because of competing priorities and structural barriers to care.

Participants also shared the belief that going to the hospital was important "because when you go late to the hospital it's difficult to be assisted." Most women emphasized their responsibility to "rush to the hospital," but a few women acknowledged that they were late, and had been "just staying" at home. Although most women understood there was a benefit of getting treatment early "in time to be healed", their intentions did not align with their ability to act on their desired behaviors.

Economic hardship and roles and responsibilities

A majority of the women did not have regular income of their own and instead relied on their husbands or families for financial support. However, some women were working when they noticed their

symptoms and delayed seeking medical attention due to other responsibilities and commitments. As Julita explained, "So when my child came, she said that the lump could cause cancer. She said that I should go to Central. That time I did not go because I was harvesting maize in the village. I also did not have anyone to leave the house with."

Stage 5: Reach the health care facility

In the figure of the framework we break this apart into two different stages: reaching the health facility for the first contact (usually a lower level health center) and then reaching the referral hospital (where a woman would be diagnosed through biopsy and receive treatment). As many of the themes of these two steps are similar, they are described together, highlighting specific examples for each possible pathway to appropriate care.

Health care connections

Malawi has a tiered health care system, where patients are supposed to follow referral channels, often requiring a note in the health passport (medical record), before going to a higher level facility. A majority of the participants went through multiple referral channels, seeking care at multiple health centers and hospitals. However, some women gained access more easily, skipping the usual referral process because they had personal connections such as a family member who worked at a hospital. Others were able to go to private facilities because their friends or family members intervened and offered financial support. This demonstrates how even in resource-limited settings, privilege and disadvantage between social groups exist based on socioeconomic position.

Distance to facility and transportation costs

Almost all participants described transportation problems due to the distance to the central hospital and the costs to get there. More than half of the patients interviewed travelled to the hospital in Lilongwe from rural villages; they used a combination of walking, hiring a kabaza (bicycle ride), paying for a minibus ride, or relying on friends with cars to reach the facility.

Although transportation was a hardship that affected both phases of reaching a health facility, once women were referred, the cost of transportation was more commonly noted as a barrier to reaching the tertiary facility for diagnostic evaluation. The distance and transportation challenges also affected treatment. One woman described how it took three months to get enough money so she could get to the

hospital for surgery. Financial assistance for transportation from family and friends was a common theme and helped women reach the health facility.

Stage 6: Receive appropriate care

The final stage of the process is to receive adequate diagnostic workup and initiate treatment as early as possible. However, patients faced provider and health system challenges which contributed to delays in receiving appropriate and timely care. Provider knowledge, access to and availability of health workers and services, processes of care, and medication availability all affected how and when women were diagnosed and started treatment.

Provider knowledge

As described in the previous section, Malawi's tiered health care system requires referrals, and many patients experienced delays due to poor provider knowledge about breast cancer and misdiagnosis of their symptoms. Many women were given pain killers from the local health center for multiple months before receiving a referral letter for the tertiary care facility. Some women's misconceptions were reinforced at the local health centers when providers failed to attribute their symptoms to breast cancer. Instead, women were misdiagnosed and told their symptoms were caused by a boil, rheumatism, or high blood pressure.

One woman described following the proper treatment channels, first seeking help from her community's HSA then traveling to the local health center, only to be sent home with pain killers. The multiple visits back and forth frustrated many patients and made them question whether the expenses were worth the trip. As one patient explained, "So my other neighbor is an HSA. I explained to her, then she was saying that maybe its BP (high blood pressure) let's go and check BP at the hospital. When they checked the BP they said there was no problem. So they just gave me just a pain killer. It is difficult. So I just stopped."

Access to providers and services

Diagnostic evaluations can require multiple visits for X-rays, blood work, and obtaining a biopsy sample. Issues concerning the availability of these service and subsequent delay came up in multiple interviews. For example, various hospital departments told some women to go home and return another day because the doctor was not available, the computer was broken, or the X-ray machine was not

working. Additionally, many women who had surgery explained how they were told a certain date for surgery, but then waited in the wards for a few weeks then went home before actually having a mastectomy.

A few women tried to use the ambulances from the district hospitals as transportation to the referral hospital, but were delayed for multiple weeks or denied a ride. As Angella explains, "When I went to get in the ambulance, the driver said, 'We are taking serious cases not someone who just comes from home and says she want to get into the ambulance'…When I heard that, I was disappointed and I gave up."

Processes of care

Generally patients have to collect their own x-ray and laboratory reports and bring them to a consultant. Lack of provider communication about collecting biopsies and misunderstandings about the procedure caused two patients to delay receiving appropriate treatment for multiple years. Both women thought the biopsy procedure was part of treatment and did not get clear instructions about when their results would be available. Each woman thought she was cured after the biopsy, and so they did not return for treatment for many years until their symptoms became severe.

Eliza: They just remove the biopsy…but they did not say, 'It is cancer' because the results were not in. So…I was admitted, I had a lump, they removed it. It went down because they did the biopsy. Since it is soft it went down. I thought that was the end of that… I thought that I had been cured… When days passed, two to three years, it's when pain started again at the same place."

Most women said the biopsy reports took "many weeks" to come back, and reported being confused about when to return to "hear the results." Women described the hardship of making the long trip back to the hospital only to be sent home because their biopsy results were not ready yet or because their samples were lost and additional biopsies were needed. For some women, these long periods without a confirmed diagnosis or treatment led to them seek help from a traditional healer or get a second opinion from a different facility.

Chemotherapy shortages and medication costs

Although treatment at the government hospital is free, many women were told to buy chemotherapy drugs at private pharmacies because of shortages. One patient described a months-long drug shortage. As she could not afford to purchase the medication on her own, she did not receive treatment. However some women were able to gather enough money from their social networks. Throughout the interviews women expressed gratitude for the generosity of their family members, friends, and neighbors who contributed to their costs of care and helped them receive treatment. Fatima recalled, "I was told that I should go and buy treatment…The main issue is money. So I tried to go and ask for assistance from relatives. So had it been that I had no relatives, that means I could not receive treatment. I would have gone back."

Discussion

Breast cancer is a growing public health concern for many African nations and effective programs and interventions require a better understanding of the underlying problems affecting late diagnosis. This conceptual framework for understanding delay in SSA considers the complex conditions, beliefs, and relationships that influence breast cancer detection, diagnosis, and treatment initiation. By exploring the decisions and interactions that occur as women seek breast cancer help, we can identify relevant interventions to address individual and social contextual factors influencing breast cancer help-seeking patterns. Therefore, our study provides highly relevant data for informing breast cancer control initiatives in the region.

Various individual, interpersonal, health care system, and social cultural contextual factors contribute to delays in diagnosis and initiation of treatment at different stages of the breast cancer help-seeking pathway. We talk about delays at various stages of the pathway and do not explicitly assign titles or blame to patients, providers, or systems. The six stages we outlined represent the experiences of Malawian breast cancer patients, although other trajectories are possible. In fact, a couple of the women we interviewed were considerably knowledgeable and engaged in their care; one woman who was a retired nurse travelled to India for care and others raised issues of quality of care concerns. But the

majority of our patient narratives indicated that lack of awareness and poor recognition of illness led women to delay seeking help until the symptoms progressed.

Symptom appraisal is often cited as a major contributor to patient delay and the influence of knowledge on health-seeking behaviors has been reported in many studies worldwide (105-107, 114). Other studies from low- and middle-income countries outside of Africa support these findings, especially that attributing symptoms to non-threatening causes delayed diagnosis (60, 121). These results are also supported by reports from other African countries, but our study provides a more in-depth description about the symptom interpretation and other factors that inhibit early detection. Many Malawian women had never heard of breast cancer, and even among those who were aware, breast cancer knowledge was low. Similar to findings from Ghana and Ethiopia we found that many women did not know that a breast lump was a sign of cancer and delayed seeking help (6, 32). Although fatalism was a common theme among Ethiopian patients (32), only a few women in our study questioned the curability of cancer and were afraid of dying; in general Malawian patients had positive views about treatment improving their condition.

Seeking care from traditional healers appears to be somewhat common in SSA countries (32, 37, 122). Local misconceptions about causes of breast cancer led some women in our study to try traditional medicine, often using herbs. This was more common among women with lower education levels and who were previously unaware of breast cancer. Although prayer was reported as a factor related to delay in Nigeria (62), we did not observe the same effect. Only one participant described her experience at a fellowship meeting where people go to be prayed over for healing and she went after she started treatment.

Limitations of this research should be noted. This study did not attempt to capture all the life experiences of Malawian women with breast cancer, but was intended to help understand reasons for delayed diagnosis and treatment initiation. We recognize that many women with breast cancer in Malawi may never reach a referral hospital where patients were recruited. Although study participants were eventually successful in accessing help for their breast cancer symptoms, many did not receive timely or appropriate care and faced many barriers before reaching the referral hospital. We highlight their shared beliefs about early treatment, but the majority of themes focused on delayed symptom appraisal,

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misconceptions, and challenges women faced in accessing care. Additionally some women initially experienced symptoms or were diagnosed a few years prior to our study, therefore their recollection of the events may not be as sharp and it is difficult to tease apart how their perceptions about early detection and testing have changed. However, we recruited women at different points of cancer care and heard similar stories from women with recent and past experiences.

Quantitative studies examining associations between delay, stage, and health outcomes are needed to determine the scope and effect of this problem in Malawi and across Africa. Although the results of this study reflect Malawian breast cancer patients, key findings may be similar in other SSA countries as well. Additionally, similar frameworks may be applied to other cancers in SSA, such as cervical cancer, and used to identify and prioritize interventions to improve cancer care generally.

These results may also be used to develop an awareness campaign to address the misconceptions raised by patients and promote breast health awareness. It will be important to tailor the messages of any future outreach programs to not cause alarm or overload the local health care facilities. The messages should focus on the symptoms, risk factors, and potential cure of breast cancer with early treatment. Although targeting women is important, any future awareness messages should also be broadly disseminated because of the influence of social networks and husbands; we found that these interactions helped encourage women to seek medical care. Additionally, promoting discussions of breast cancer may help increase positive attitudes about treatment and motivate women to seek medical care sooner. Distance to facilities and transportation costs were commonly mentioned as barriers along the breast cancer help-seeking pathway; therefore expanding detection services at local health centers may help increase availability at more easily accessible facilities. Indeed, transitions in care were troublesome for many women and delayed referrals for diagnostic evaluations and treatment initiation. Ensuring providers at local health centers have been trained on breast cancer symptoms may reduce misdiagnoses and speed up referrals for suspected cancers. And improved processes of care at district and central hospitals may address logistical delays patients faced between consultations, biopsy sampling, biopsy reports, surgery, and chemotherapy. Finally, interventions to provide counselling and support services to patients upon arrival in the oncology clinic might help patients navigate the diagnosis process more easily and increase patient understanding of diagnostic procedures.

Conclusions

Many breast cancer patients in Malawi experienced long delays between symptom onset, reaching the health facility, being diagnosed, and initiating treatment. Generally low awareness of the disease and poor knowledge of symptoms delayed women's decisions to seek help, but this research also illustrated how health care system and social factors contribute to challenges in accessing cancer care. Women were strongly influenced by interpersonal relationships, which had positive effects and negative consequences on women's help-seeking behaviors and receipt of cancer care. Overall, this framework provides a more nuanced consideration of help-seeking behaviors and social-contextual factors affecting breast cancer delay. By understanding the ways in which poverty, cultural beliefs, social interactions, and health system factors affect decision-making processes and women's ability to access care, it is possible to design and improve interventions aimed at cancer early detection in SSA. Focusing on stages and transitions of the breast cancer help-seeking pathway illuminates opportunities to influence care and reduce delays for breast cancer and possibly other cancers.

Table 4.1. Characteristics of Malawian breast cancer patients	
	Number (%)
Age group	
25-40 years	9 (45)
41-55 years	4 (20)
56+ years	7 (35)
Marital status	
Married	15 (75)
Single/divorced	2 (10)
Widowed	3 (15)
Religion	
Christian	18 (90)
Muslim	2 (10)
Residence	
Lilongwe	12 (60)
Outside of Lilongwe	8 (40)
Education	
No formal schooling	5 (25)
Some primary school	8 (40)
Some secondary school	7 (35)
Economic status	
Electricity in house	5 (25)
Regular source of income	8 (40)
Roof type	
Iron sheet roof	11 (55)
Grass thatched roof	9(45)
History of cervical cancer screening	5 (25)

Table 4.2. Factors affecting stages of the breast cancer help-seeking pathway

	Stage 1: Notice and interpret initial symptom	Stage 2: Monitor changes and infer illness	Stage 3: Decide to seek help	Stage 4: Intend to seek help through traditional remedies, social network, or medical care	Stage 5: Reach the health facility (initial facility and/or referral hospital)	Stage 6: Receive appropriate and timely care
Individual level	Nature of the symptom, breast cancer awareness	Knowledge about symptoms, misconceptions about causation, other health concerns	Visible symptom progression, emotional response, perceived risk	Beliefs in traditional medicine, religious beliefs, economic hardship		
Interpersonal level			Cancer-related experiences among peers	Social support and encouragement, cancer-related experiences among peers, experiences and perceptions of facility quality, family roles and responsibilities	Financial support, health care connections	
Society and health system level			Health-seeking practices, trust in providers, positive attitudes about medical interventions	Cultural attitudes about the importance of testing and benefits of early treatment	Distance to health facility, transportation, referral channels, provider knowledge of breast cancer	Misdiagnosis, access to providers, process of care, medical equipment failure, medication availability, provider communication

Notes: Social demographic characteristics (age, gender, marital status, education, residential area, occupation, social economic position) and culture are influential across all stages of the breast cancer help-seeking pathway

Table 4.3. Occurrence of coded text units from key themes in interviews with Malawian breast cancer patients

Code/Concept	Total text units	Illustrative quote
Lack of awareness	20	"Aah, I have never heard about breast cancer. I have just learned now that there is also breast cancer, but I didn't know that there is also breast cancer. I was just hearing that there is cervical cancer but I did not know about breast cancer or what it looks like. I am seeing it now that breast cancer looks like this."
Other explanation for symptom	37	"I just thought it was one of the boils which people have, they remove the puss from them…I thought it was just a boil. Then I started to suspect that maybe it was not just a boil because it felt hard…[and had] a type of pain that made me restless. I could not wear anything. I had no peace. My heart was beating very fast."
Symptom prompts action	37	"For me to know that I had a problem…whenever I felt the breast, inside the breast, there was something hard. Feeling the other one, it was ok. I saw that the thing was getting bigger. Yes, That was when I realized that my breast has a problem which is causing these symptoms. That was when I went to the hospital."
Decide to seek help	38	"I did not take time. I was telling them so that maybe they will tell me that I should [go to] such and such place - to the appropriate place because if I hide, I could not get the right help."
Risk perception	35	"Because they were pressing it, at the clinic, here, they were pressing it to see the lump. Yes. So when they pressed it very hard, There was blood and some colorless fluid coming from the nipple. That was when we believed that it was cancer. Yes it was cancer. Leaving it like that could have made it worse. Maybe it could have spread."
Cancer-related experiences	39	"I heard that there is this problem…I saw a person in the village. Her breast was removed…I heard that it is a dangerous disease. And I saw my friend whose breast was removed. She is not alive. In the same year when her breast was removed, she died."
Consult lay people	47	"It was December, in the same month my daughter came for Christmas. That was when I told her that I was examining my breasts on the bed and I felt something inside the breast. Yes. Because sometimes it was itchy because of the fluid that was coming out. It was itchy. I was scratching it. So when she felt it, pressing it, feeling the breast that was when she said it was cancer. And that I needed to go to Central. Yes, that was how I realized that it was cancer."
Traditional remedies, witchcraft	28	"The first thing I did, There was one of my relatives, who told me that I should be heating a cooking stick and put the cooking stick on my breast…The fire was a part of treatment…I did not see any change. That was why I just decided to come to the hospital."

Early treatment benefit	42	"It is important to go quickly to the hospital when you see a strange thing. So that they [health workers] should check you what the problem coming is. Don't just stay at home. Because when you go late to the hospital it's difficult to be assisted."
Positive attitudes toward medical interventions	55	"Because it is the hospital that saves a person from the disease that they have. Because when they stay at home on their own they cannot be helped. So we do come here to the hospital for the disease that we have, so that they can help us to get treatment"
Importance of testing	15	"You have to know about your body. Even if you are just suspecting that you are not feeling well. The most important thing is to get tested, testing is the better way. To know what is wrong with you. Instead of just staying [doing nothing]. You should not fear the hospital"
Provider trust	21	"We listen to what the doctor says. Because the doctor knows, he was trained in many things. You don't know anything. So if he tells you to do something, You have to do it."
Referral delay	12	"So in January I went again to [the clinic]. When I went there again and explained to them they just give me medication. I took the drugs. They said when there is no change I should come back. I went there three visits. I was just given drugs. Now on my fourth visit, I was given a referral that I should go to gynae [gynecological department]. They should check, they are who checks lumps When I went there they just checked me and gave me referral to Central. So I came here"
Provider lack of knowledge delay	6	"They were just telling me it's a boil. They were giving me medication, injections. The lump was not going away. So I went and told them, 'It is not going away, it is just getting bigger.' So they told me, 'Go back home so that the boil can break. Do not remove the puss at home. You should come here so that we see it.' So when it got bigger and showed the signs of breaking, I went and said, 'Have you seen how it is? I have no peace.' That was when they said, 'Go!'"
Distance to facility	33	"I was worried about transport from Chinsapo to here [central hospital]. If it was near, I could have been coming sooner."
Transportation costs	25	"Because we rely on farming in order to find money for transport… [we were] waiting until we sell tobacco to find money to use for transport to go."
Economic hardship	28	"The problems that I have experienced, although I work, I just work because I have no assistance. Had it been that I was well to do, I could have just be staying (at home). But because I have needs, I am forced to work instead of being assisted. But this year it has been tough for me. I did not do farming because of my condition. There was a lump in my armpit, if I ever walked for a long distance, I had to lie down. So I stopped leaving my home…The way I was before, I was very strong. I was able to work but now it is difficult for me to work. I try to work, but as I am saying that when I work, I do not

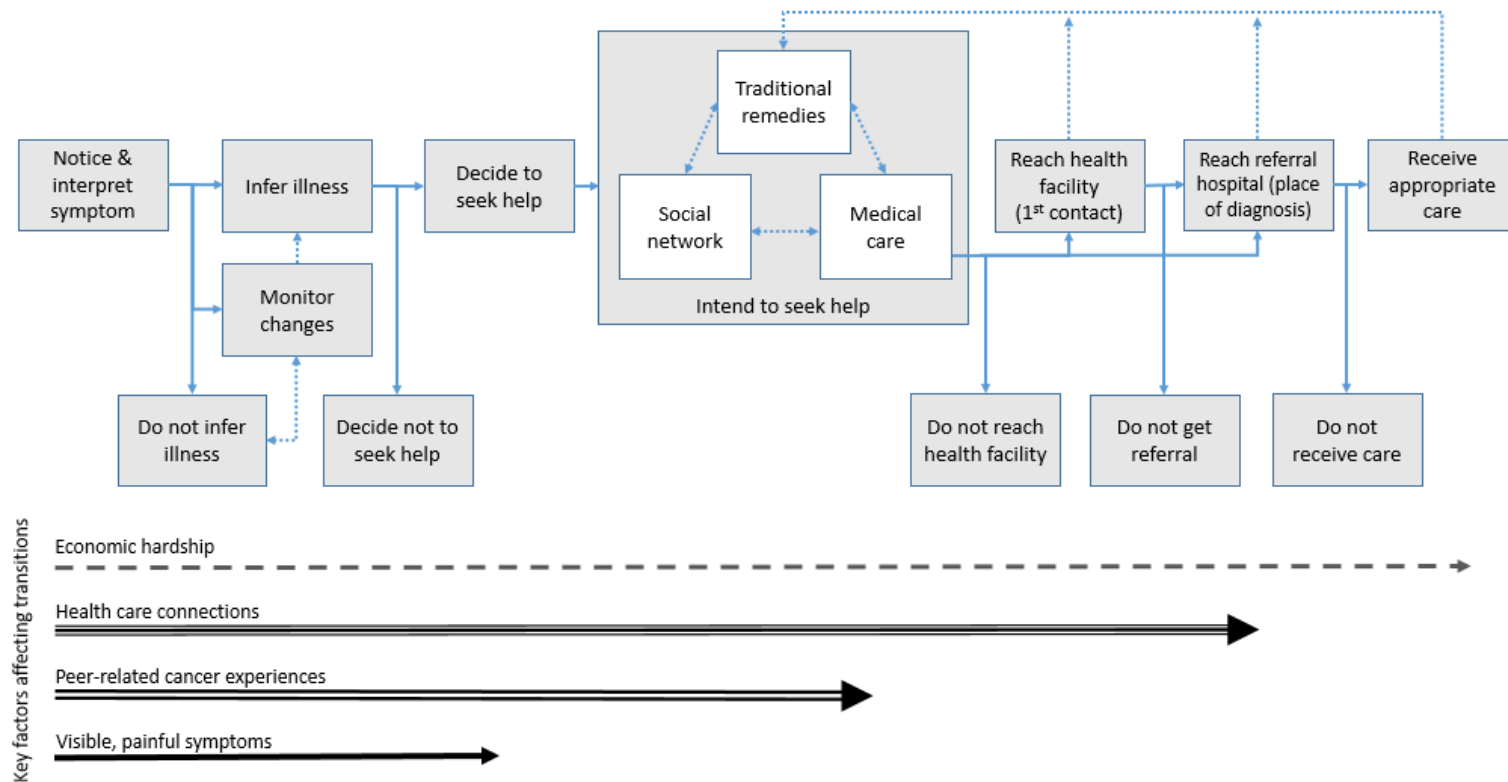|		
		feel fine. I don't feel good at all. But I have nothing else to depend on. That is why I continue work. This year I do not know what I will do since I did not do any farming."
Family support	34	"My children are the ones who help me…giving me transport. And also I live in the village in Ntchisi but when I come, the children are the ones who help me. I stay in their houses."
Access to providers and services	35	"Because when I came in August, they did the biopsy, They said, 'You should come on the 27th.' I came on the 27th. They said, 'There is a strike.' So I went back. I did not receive treatment. I came back in January."
Medication availability	15	"But the problem, was that when we came here for treatment sometimes, when we went to the pharmacy to receive medication, some medications were not available. [They said,], 'No. This medication is not available.' That was the problem...But we just saw that after four months, we started receiving medication normally. They said that the medications were available."
Poor processes of care	44	"When they tested me after taking the sample…it took three years for me to know that it was cancer because they took it to Blantyre. In the first year, it got lost. They took another sample. It got lost again. During the third time, that was when they diagnosed cancer of the breast."

Key factors affecting transitions

| Notice & interpret symptom | → | Infer illness | → | Decide to seek help | → | Intend to seek help | | Reach health facility (1st contact) | → | Reach referral hospital (place of diagnosis) | → | Receive appropriate care |

(The figure content is a flow diagram.)

Traditional remedies

Social network ⟷ Medical care

Intend to seek help

Monitor changes

Do not infer illness

Decide not to seek help

Do not reach health facility

Do not get referral

Do not receive care

Economic hardship

Health care connections

Peer-related cancer experiences

Visible, painful symptoms

Figure 4.1. Breast cancer help-seeking pathway in sub-Saharan Africa

Notes: Dotted lines along the pathway indicate options trajectories (e.g., some women may seek help from social networks and medical care, but not traditional remedies). Among the key factors affecting the timing of transitions through phases, multiple, thick lines indicate faster movement and the lighter dashed line represents slower movement.

CHAPTER 5: DEVELOPING A DISCRETE CHOICE EXPERIMENT IN MALAWI: ELICITING PREFERENCES FOR BREAST CANCER EARLY DETECTION SERVICES

Introduction

Breast cancer rates are increasing in African countries (1), yet few have successfully adopted national cancer control plans or breast cancer early detection programs. Mammography is not widely available due to high infrastructure costs and human resources it requires; therefore, many African countries rely on more pragmatic approaches to early detection, such as clinical breast exams (CBE), and promoting breast health awareness (41, 43). The Breast Health Global Initiative consensus statement suggests CBE may be the most resource-appropriate screening strategy in most African countries with limited resources; however, evidence regarding the feasibility and efficacy of detection and screening strategies in these settings remains unclear (42).

Defining conditions under which women would choose to participate in breast cancer early detection interventions would allow policymakers and ministries of health to base future programs on evidence. Previous studies from Africa suggest that lack of services, low breast cancer knoweldge, privacy concerns, lack of transportation, and women's roles and responsibilites may influence breast cancer early detection and diagnosis behaviors (33, 42, 51). However, to date, no studies have assessed African women's preferences about different breast cancer early detection methods.

Preference elicitation techniques, such as discrete choice experiments (DCEs) and best-worst scaling (BWS), provide information about the value of hypothetical new services or delivery models or to estimate their potential uptake and utilization (89). These survey techniques are based on the premise that a good or service can be broken down into separate attributes, or characteristics, and the total individual preference for using a service is made up of the individual preferences of the attributes of the service (89, 91, 92). A DCE involves presenting respondents with hypothetical scenarios in a choice set

and forcing respondents to choose between the scenarios in order to understand trade-offs between attributes and levels of attributes (91).

Applying a DCE to breast cancer detection in Africa could be valuable to determine women's preferences for future interventions, but the relevance of a DCE depends on identifying locally appropriate attributes and defining levels of the attributes that are plausible in the local context. Qualitative methods are recommended to understand important characteristics of the service and to help identify attributes and levels which the target population deems relevant (85, 123). Additionally, some studies suggest that preference elicitation techniqes are complex and may be difficult for populations with lower education levels, literacy, numeracy, or mental capacity to comprehend or use meaningfully (124, 125). The objective of this study was to understand factors that affect women's intentions to use cancer detection services, to identify and select relevant attributes for a DCE, and to determine the optimal design of a DCE and its feasbility and acceptability in Malawi.

Methods

Study setting

This study was embedded within a larger mixed methods study of breast cancer knowledge and preferences conducted in Lilongwe, the capital of Malawi. The government provides basic health services free of charge through local health centers dispersed among rural villages, district hospitals, and central referral hospitals (126). The remaining proportion of health care is provided by mission hospitals, which are partly subsidized, and private clinics, which charge fees (127). Because of physician shortages, clinical officers, who undergo a shorter medical training compared to physicians (128), provide care in various primary and some specialty care settings.

Accessing health services is difficult for many Malawians, especially those lacking formal employment, economic stability, and transportation. Regarding breast cancer services, pathology and chemotherapy in Malawi are currently available at two large teaching hospitals in Lilongwe and Blantyre (76). Mammography is available at a private clinic in Lilongwe for approximately $150 USD, but the national service delivery guidelines recommend CBE and education on breast sefl-exams (BSE) and no

national breast cancer screening program exists (79). However, screening for cervical cancer has increased in the last decade and is available at many lower level health centers across the country (129).

Ethical approval for this research was granted by the University of North Carolina Institutional Review Board and the Malawi National Health Services Research Committee.

Literature review

The attribute development process began with a literature review focused on breast cancer detection services in sub-Saharan Africa. The search was conducted using Pubmed, Web of Science, and Google Scholar databases and included published articles in English from 2000-2012. We used combinations of the following search terms: breast cancer, early detection, screening and discrete choice experiment, conjoint analysis, best worst scaling, and preferences. Additional articles were obtained through manual review of reference lists of retrieved articles. In this paper, we focus on the findings from preference studies regarding breast cancer screening as well as DCEs applied in other African settings.

Qualitative data collection

We conducted individual in-depth interviews from April to August 2014, to provide a rich understanding of the factors affecting women's choices regarding preventive health care and early detection of cancer (123). We recruited 10 health care workers (HCWs) who provide routine women's health care from multiple departments of a public referral hospital, district-level hospital, and public trust clinic for HIV patients. The semi-structured interview guide included broad topics such as cultural perceptions of cancer, health system factors affecting cancer diagnosis and treatment, and knowledge and attitudes regarding breast cancer and early detection methods, as well as demographic and employment information. HCW interviews were conducted in English, recorded, and transcribed verbatim. On average, the HCW interviews lasted about 1 hour.

We also recruited 20 community residents and women attending family planning and reproductive health clinics because they were identified as potential target clients of future breast cancer detection services. Local interviewers conducted and digitally recorded individual interviews in Chichewa, the local language. Semi-structured interview guides collected demographic information about the participants as well as their health seeking behaviors and breast cancer knowledge, attitudes, preferences, and practices, including breast and cervical cancer as well as general preventive health care. At the end of the

interview, the interviewer reviewed a fact sheet about breast cancer signs/symptoms, risk factors, and detection strategies. The interviewer informed each participant about CBE and BSE, but did not conduct an exam or provide formal instruction on BSE. Interviews lasted 35 minutes on average and were transcribed verbatim, then translated into English using an experienced translator.

We used Atlas.ti 7 (Atlas.ti Scientific Software Development, Berlin, Germany) to code the transcripts. Two coders independently applied a common codebook based on conceptual domains identified in the literature review and the social contextual framework (83). We revised codes and definitions as additional themes emerged. After applying the final codebook to all transcripts, we reviewed common co-occurring themes and looked for patterns within and across HCWs and community transcripts.

Designing the choice experiments

The data collection team worked with community outreach leaders, who lead a local community advisory board and are responsible for community education and sensitization programs, throughout the development of the DCE. After reviewing preliminary results of the qualitative interviews, we discussed the relevance of potential attributes to determine a smaller subset. We also identified plausible levels for the attributes based on responses, such as common transportation costs, reported travel times, and frequently mentioned health encounters. We used Sawtooth Software 8 (Sequim, Washington) to design two choice experiments and used hard copies of choice cards with images. We proceeded to evaluate patient understanding of the DCE using cognitive interviewing methods described below.

In addition to the DCE, we developed a BWS exercise to determine which approach was more appropriate for the target population. BWS, also called maximum difference, is a discrete choice task in which a person is asked to select the best and the worst (or most important and least important) aspect within a scenario instead of choosing between scenarios (130). This exercise has potential to produce robust data about the importance of attributes and levels at a lower level of cognitive burden (131, 132).

Cognitive interviews

We purposively recruited eight low-income and/or low-literacy women through the community advisory board contacts to test the experiments and to check the adequacy of the attributes and levels. A trained interviewer described the attributes and levels and corresponding images, introduced the

experiments, talked through a practice example, and administered the DCE and BWS experiments. The interviewer asked participants to think aloud as they made their choices and probed about the difficulty of the choices, comprehension of the attributes and levels, and acceptability of graphics and how they influenced understanding. The interviewer took detailed notes on the participant's responses and whether or not she had difficulty with particular choice sets, wording, or images; each cognitive interview was also digitally recorded for analysis. At the end of each interview session, the interviewer wrote a detailed summary and debriefed with the rest of the data collection team to review problematic areas and make revisions.

Results

Identifying relevant attributes and levels from the literature

Because no studies from low-income countries have explored breast cancer detection preferences, we relied on studies from high-income countries which examined characteristics of mammography screening services (86, 87, 133-137). Additionally, we identified one study that assessed preferences for BSE education (88), but none about CBE. We identified common conceptual domains including attributes about the invitation or reminder to participate in screening, convenience, facility setting, privacy, accuracy and frequency of the intervention, and how results were relayed. In light of the Malawian context, we also considered how other DCEs conducted in Africa described and presented health interventions, and considered additional concepts such as provider characteristics and health infrastructure (138-141). We used the list of potential attributes and levels from the literature (Table 5.1) to develop probing questions for the community and HCW interview guides so we could explore these concepts in more detail.

Sample characteristics

The majority of HCWs we interviewed were female nurses; the mean age was 37 years (Table 5.2, top panel). We purposively recruited workers from different departments including, oncology, surgery, obstetrics/gynecology, casualty, and HIV care. They had been working at their current job for on average 3 years, and the mean professional experience was 12 years (ranging from 1-35 years). Five of the HCWs provided cancer treatment, and two provided cervical cancer screening services.

The mean age of community participants was 42 years (Table 5.2, bottom panel). The majority of women were Christian (18/20) and married (11/20). In terms of education, six women had no schooling, nine had some primary education; only 5 attended secondary school. Seven of 20 women reported a regular income, and 5 had electricity.

Distance to the facility and travel time

The most common factor community women mentioned about why they chose to use certain health facilities was the distance or travel time to get there. Most women walked to the nearest facility and described how the transportation costs to other hospitals were prohibitive. Some hired a ride on a bicycle or took a minibus to their preferred facility when they had money. However, few women were able to estimate how far they travelled; instead they described how long it took to walk and reach the facility. The HCWs also acknowledged the importance of distance and transportation costs as the primary drivers of where women sought care. But both groups mentioned that facility choices also depend on the severity of the health condition. Some women were willing to travel longer distances for specialty care at different facilities versus "for lighter ones [conditions] I can go to clinics."

Costs of care and perceptions of quality

Although the women from the community described many differences between government and private facilities, most used government hospitals because "they are free, you don't need to pay anything." For some, their lack of financial resources kept them from accessing their preferred facility and led to them delaying care because of the costs. One woman explained:

> "The hospital which is near is private. So because of the prices they charge there, sometimes we cannot afford it and Area 25 health center (public facility) is far. As a result you just decide not to go the hospital anymore. As a result the problem worsens."

HCWs suggested that future services should be established and expanded at government facilities because "most people here are poor so they would come to a government institution where there are free services."

However, some women chose between nearby health centers based on past experiences or recommendations from their social network. The quality of services, especially the availability of medications or working equipment at the facilities affected their preferences. Staff attitudes were also

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important, as one woman reflected, "It is how they welcome us…[if] they receive us well when we go and tell our health problem." HCWs also noted that facilities can get "overwhelmed with a lot of patients coming each and every day" and that patients are sometimes "sent back if the resources are not there," which may affect where patients choose to get care.

Still other community women felt that they had no choice because of the referral requirements to get to the central hospital. As one participant described, "We do not choose because you are supposed to go to your clinic first, then at the clinic they will refer you to central." Similarly, HCWs thought it was important to offer cancer detection services at lower level health centers because that is where patients go first before being referred. But some also thought detection services should be provided "across the health system starting from the HSAs (health surveillance assistants) to the health care centers and the district hospital."

Preferred health care workers and gender

Although the community women spoke generally about "doctors" and rarely differentiated among types of HCWs, the HCWs we interviewed had opinions about who should conduct a CBE or teach women about breast health and self-exams. The two clinicians suggested that clinical officers should do CBEs because they might be more knowledgeable about breast cancer, and that antenatal care (ANC) nurses already perform breast health education and could increase those efforts. The nurses proposed that community workers and HSAs do the education and that breast cancer patients should get involved because they could give testimonies to encourage early detection. But the community women did not discuss preferences for doctors over nurses; they only made a distinction between HSAs and other health workers because HSAs are in the community more and wear uniforms. However, their discussions did not indicate strong preferences for doctors or HSAs.

Additionally, patient-provider communication was mentioned as a potential factor in women's decisions to seek cancer detection services. A few of the nurses thought some patients might be afraid of the hospital and HCWs if they suspect cancer, because they might be scolded for delaying care and presenting with advanced symptoms. Another nurse explained:

"There might be health workers who are not good at communicating, especially like breaking bad news. Being told you have cancer is bad news. So we may have people who are not tactical

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enough when they are breaking the bad news, so people are afraid of them. So people are afraid

of that - the way you are told, 'You have cancer, so there's nothing we can do.'"

Community women's preferences for male or female HCWs also varied depending on the health

issue or type of exam. Many women said if possible, they would prefer to be seen by a woman for a CBE

because they would feel shy and embarrassed if a man attended to them. One woman explained:

"We women would love to be checked by our fellow women. But the way we know how doctors

are at the hospital, it is mixed…so when we go to the hospital, we don't have the power to

choose, like to say I want to be checked by a female doctor."

Some women recalled having a male HCW during delivery of their children, and accepted whoever was

available because, "There can be no shame. I should just say a doctor is a doctor." This attitude seemed

to stem from women feeling that they had no choice as one participant explained, "you are sick, you don't

have the freedom to say that you should not assist me, that this other one will assist me."

Interestingly, a few community women preferred male HCWs because they thought females were

"cruel" and did not ask questions or take notes about their complaints; participants told stories of how

female HCWs assumed a lot about the patients and "they just say bad things to you, so we do not like

them." Whereas the male workers they encountered were more thorough during exams and gave "better

treatment," so some women trusted "the male ones because they show that they have a passion in their

job."

Privacy

We also found different preferences regarding privacy. Although community women talked about

breastfeeding on the minibus, in church, and walking down the street, they thought breastfeeding was the

only appropriate time for a woman to expose her breasts publicly. However, some did not consider their

breasts to be "private parts." Most were not embarrassed to expose their breasts during a physical exam,

but felt shy if they were asked to expose their "private part down there" for a pelvic exam or cervical

cancer screening. The Muslim participants said undressing "everywhere" or "down there" for a male HCW

was "not allowed" and a few other women had similar preferences for females doing pelvic exams for the

same reason. One woman explained, "The problem is down there. The breast is not a problem…as long

as you are sick." This caveat about accepting a male HCW as long as you were sick was common.

Participants usually went on to say that it was okay for a male HCW to do the exam "because he was trained" but often clarified that it was acceptable because "you need treatment."

The importance of testing in a culture of curative care

In a country that has faced a significant HIV burden, it is not surprising that the importance of "*testing*" was a common theme that emerged. Nearly all the community women spoke positively about going to get checked because, "you think you are ok but maybe you are not ok…when you go to the hospital you are able to know" and they thought getting tested was "better than just staying" at home delaying. However, this was usually discussed in the context of a suspected health concern or symptom. Women were cautious about going to the hospital when they were not sick and worried whether they would be helped. Some thought going without a complaint was inconvenient to doctors or a burden on the health care system (e.g., "giving them (doctors) problems"). A few noted the main issue was the lack of a specific facility where people could go for a well checkup or general physical exam, "so we usually wait until we are sick... that's when we seek medical help." Another woman described:

"It has been established that we wait until we are sick…The problem is that when you go to the hospital while you are not sick, I don't think they can assist you. They will just say, 'Why are you coming here? You are wasting our time. We should assist the people who are sick.' "

Similarly the HCWs shared the perspective that people in Malawi have "poor health seeking behaviors. We only want people to come to the hospital when they are sick." These sentiments often preceded discussions about staffing shortages and overcrowded hospitals. A few recalled how they had turned people away because of "queues and queues of sick patients." These attitudes and health infrastructure challenges likely have implications for access to and demand for cancer detection services because "when they (patients) come and ask if they have the disease, we will ask them, 'Why are you here? You are not sick. Go back.'" Nonetheless, they thought it was important to promote general health exams and suggested establishing "clinics where someone can just go for medical checkups" or a dedicated "breast clinic" for education, exams, and counseling.

Bundled services and point of entry into health system

We also explored whether community women would be interested in coming for early detection services alone and how they could be integrated into other pre-existing services and routine care. Many

of the community women said they heard about BSE and/or breast cancer from a health talk at family planning or a community health gathering. Participants from both groups thought CBEs would be more convenient if they were added to frequently used services, such as under 5 child health checkups, HIV voluntary counseling and testing, and cervical cancer screening. One nurse suggested,

"Then it will be much easier for the patient...because she comes for VIA (visual inspection with acetic acid) but at the same time her breasts are examined for breast cancer, rather than her going home and coming back again another day for this other examination."

HCWs also recommended emphasizing education beyond family planning and ANC visits . They thought that taking advantage of the large crowds in waiting areas to educate women on breast cancer, BSE and CBE might reach more women. These common, routine health encounters and health talks were cited as important opportunities to use the point of entry into care to offer additional breast cancer detection services and education.

Breast cancer risk perception and detection methods

In general, community women knew very little about breast cancer, signs, symptoms, or detection methods. They also had a low perceived risk of breast cancer and seemed more interested in early detection to make sure they were healthy enough to continue working, not because they were worried about having cancer. Only one participant said she feared the results and was hesitant to get checked; the rest of the women said it was "good to know how your body is." They did not seem worried or anxious about having an exam that specifically looked for cancer as one woman explained:

"That would not be a problem because I need to know…once I know, the doctors can treat me in time. Whether I have it [cancer] or not, it is good…it is better to know instead of not knowing because nothing can help you. You can just be living in ignorance. When you are told, you know."

Most of the community women were interested in "getting tested" but they did not know what the test was. When asked specifically about having a CBE, nearly all of the women were willing and a majority asked for the fieldworker to do it at the end of the interview. Participants were eager to learn more about breast cancer and how to do BSE; they often wanted to invite their neighbors to come over at the end of the interview so the fieldworker could tell more people about breast cancer.

We also asked HCWs about differences in detection modalities. Only four were aware of mammography; one said, "Of course, I don't know much. I just heard it…" and another said he remembered learning about a machine to look for breast lumps in school. Only two knew that mammography was available in Malawi. Instead, the HCWs suggested educating women on BSE was a good way to help address breast cancer control in addition to CBEs. Interestingly, a few women brought up the point that HCWs were more knowledgeable than they were themselves about detecting breast problems. One woman questioned the accuracy of BSE and noted that she might miss a potential problem. A few other women were more interested in a CBE than BSE as one women described, "I cannot recognize my problem myself but the doctor was trained on that."

Selecting the final attributes

After reviewing the responses, the data collection team and community outreach leaders discussed the feasibility of incorporating the emergent themes into a new breast cancer intervention and whether we should include those characteristics in the DCE. For example, we discussed where and how the services could be offered given the local context of care, and which types of facilities might be willing and interested in establishing an intervention. We narrowed the list of attributes in order to reduce the cognitive burden of the DCE while trying to reflect the range of situations women might experience. Based on the interviews, we decided to frame the choice within the governmental context and did not include a cost component for the service because public services are free. Instead, we included a quantitative attribute regarding travel time to estimate the relative value of other attribute levels. Due to the lack of local data regarding breast cancer risk and the limited access to mammography services, we did not include risk, mammography, or accuracy of detection methods. The final attributes and levels incorporated into the choice experiment (marked in final column of Table 5.3) were travel time (<1 hour by foot, 1-2 hours by foot, or >2 hours by foot), health worker type (doctor or HSA), health worker gender, health encounter (health talk in facility waiting area, community health gathering, cervical cancer screening, family planning clinic, or child under 5 clinic), and breast cancer early detection strategy (breast health awareness, clinical breast exam, or combination of awareness and exam).

Testing the choice experiments

During the cognitive interviews, an interviewer tested interpretation problems to determine the validity of the levels in the scenarios. Respondents had a hard time understanding what "breast health awareness" meant. They wanted to know whether it was just an explanation and suggestion to "feel for lumps," whether it would include a demonstration, or whether they would receive instructions on how to conduct a BSE. Respondents thought the ranges of attribute levels were acceptable, but they also brought up the relevance of the different health encounters; for example, an older woman said she no longer needed family planning, so she thought the health talks and cervical screening visit were more convenient.

We explored how participants preferred to learn about the attributes -- for example, whether distance to the health facility should be described by kilometers, travel time, or the cost of a minibus ride. Most of the women preferred walking time, except one woman who lived in town and thought the minibus cost was easier to understand. Because a large portion of the target population lived in rural areas and likely had to walk a long time before getting on a minibus, we used walking time in the final DCE.

We also tested the BWS exercise to assess the importance of different attributes. Women had trouble choosing only one most and one least important item; there were too many options and women were confused about what to do. They wanted to say yes or no whether each level was important. Although one woman preferred the BWS exercise to the DCE, the rest commented that the DCE was easier because it required "one choice for the full thing" rather than "picking only one good thing" from each scenario.

The responses indicated that the DCE was feasible and women understood the tasks. When we asked respondents to identify differences in the scenarios, they were able to discuss differences and mentioned that the introduction helped them understand the differences in the attributes and levels. As they worked through the choice sets, we assessed whether they were able to make tradeoffs. The women were able to explain the rationale of their choices. For example, one woman noted how she was mainly interested in the CBE, "I want the [clinical] breast exam no matter how far I have to walk."

Because most of the respondents had only a few years of primary school, they relied on the interviewer to read each scenario aloud and compared the options by looking at the cards. The women

described how it was helpful to hear the full scenario described almost like a vignette, instead of just reading each attribute-level of the scenario. To them, it was important to look at the full picture and compare the two scenarios on the card as they made tradeoffs. They also noted how the images helped them understand the differences between each scenario and answer faster.

Based on the feedback received, we revised the attribute-level descriptions, updated our graphics, and summarized each hypothetical scenario to be read aloud to the participants. An example of one of the DCE sets is displayed in Figure 5.1.

Discussion

This article describes the results of a systematic, qualitative process to develop attributes and levels for a choice experiment regarding a rarely used prevention service in a resource-poor setting. We describe major themes and preferences regarding breast cancer early detection in Malawi as well as the results of cognitive testing to determine the feasibility of administering a DCE in a low-literacy setting. We found that despite women's low socioeconomic status in a health system with limited resources, patient preferences and experiences strongly influenced why and where women considered seeking services. The qualitative interviews helped provide realistic attributes and levels that enabled tradeoffs when we tested the design. The final attributes included in the DCE were travel time, health worker type and gender, health encounter type (point of entry), and breast cancer detection strategy.

Distance to the facility, transportation costs, and perceptions of quality were important considerations of preferred health facilities. Though most preferred the nearest free facility, some women were willing to travel farther to get specialty care, which may be an important distinction for cancer detection services if women notice symptoms or have a breast concern.

Preferences about the gender of HCWs varied. Despite feeling like they had no choice regarding HCWs, community women, especially Muslim women, expressed privacy concerns about physical exams by male health workers. Generally women indicated that they would prefer a female HCW, but some preferred men. This may be due to the strong trust in HCWs, paternalistic health system, and perceptions of the hierarchy in local practice; for example one woman noted, "When the nurses fail they do call a male doctor." Cultural and religious beliefs may influence social attitudes and be barriers to CBE (40, 48) (3).

Women's discussions about health infrastructure challenges and going to the hospital for preventive screening highlighted potential social norms and structural factors that may influence demand for cancer detection services. Attitudes and preferences about going for testing and accepting male HCWs only when sick may have implications for barriers to early detection among asymptomatic women. The HCWs in this study were optimistic about integrating early detection into other health encounters to increase access and uptake, and the women seemed interested. Previous studies from South Africa, however, have had mixed results after combining breast and cervical cancer screening interventions (52, 142).

When we tested the choice experiments using cognitive interview methods, we found that women preferred the DCE over the BWS design because they felt restricted to choose only one best and worst option. Our findings supporting the validity and acceptability of the DCE format are similar to a recent study comparing BWS and DCE approaches at a university campus in Australia; the authors observed that participants had trouble choosing the worst attribute level and wanted to rank all the options in the scenario (143). Women in our study were able to complete the DCE tasks and were able to make tradeoffs comparing the scenarios side by side. They found it helpful to hear a description of the full scenario and follow along with images. The literacy rate of the adult population in Malawi is approximately 61%, suggesting that a large proportion of the adult population cannot read and write (144). Thus it was imperative that our DCE included images of all attribute levels to help improve respondents' comprehension of the scenarios. The DCE design was ultimately chosen to ensure participants understood and could engage with the choices and to help address the low literacy of participants.

Despite these strengths, we must address some limitations of this study. The nature of this qualititave research and the small sample size limits the generalizabilty of these findings. Additionally the participants' knowledge of breast cancer and detection methods was low, which may have limited their responses. However, a few participants had previous experiences with detection methods (e.g., BSE) and other types of cancer screening. We also asked about prevention services more generally so others were still able to engage in meaningful discussions about aspects of early detection. In terms of developing the DCE, we may not have accurately described all the attributes some participants consider important and

relevant in the DCE, but we included the attributes that the majority of participants discussed that could potentially be tailored for future interventions.

This is the first study, to our knowledge, to develop a tool based on the breast cancer detection preferences of low-literacy and low-income women. Although we set out to develop a context-specific preference tool for use in Malawi, our findings are far-reaching beyond this specific setting. This DCE may be applicable in other African countries with appropriate modifications, and could potentially be adapted to additional types of prevention services, such as cervical cancer screening. In addition, since this study began, other DCEs in African settings (145, 146) have been published, including two conducted in Malawi (147, 148). They confirm the potential to apply DCEs more widely in African populations to inform policies and interventions to reduce health disparities.

Conclusions

We present detailed information about how we developed and tested a preference elicitation tool for breast cancer early detection in a region where early detection is uncommon, preferences regarding health care choices are unknown, and few DCEs have been administered. We identified complex factors that influence Malawi women's choices about whether to participate in early cancer detection services. Our findings suggest that assessing breast cancer detection preferences through a DCE is feasible in Malawi and possibly other low-income, low-literacy populations in Africa. A better understanding of women's preferences may help determine how detection services should be delivered in Malawi and has potential to improve uptake and acceptability of future breast cancer early detection interventions.

Table 5.1. Potential attributes and levels for cancer services compiled from the literature

Conceptual domain	Attribute
Psychosocial (133-135)	Risk of dying from breast cancer
	Physical discomfort
	Embarrassment
Invitation (86, 133, 137)	Invitation method
	How much information is shared
Convenience (86, 87, 133, 136)	Scheduling delay
	Availability of services, open hours
	Distance to facility
	Transportation costs
	Travel time
	Waiting time
Facility infrastructure (87, 136, 138-141)	Setting (health facility, community, pharmacy, mobile unit)
	Availability of drugs and medical equipment
	Cleanliness of facility
Privacy (86, 88)	Demonstration, instruction on own breast
	Size of education class
	Changing area (private or open)
Provider (86, 138-141)	Provider type (doctor or nurse)
	Technical skills of staff
	Gender
	Attitude, personal manner of staff
Intervention	Mammography
	Digital mammography
	MRI and nuclear evaluation
	Breast self-exam education
Accuracy (86, 133, 134)	Accuracy of detecting cancer
	How good the test is at saying you don't have cancer
	Risk of follow-up
Frequency (86, 134)	Number of tests performed over next 25 years
Results notification (137)	Time to results
	Mode of results
Costs (88, 133, 139, 140)	Cost of test

Notes: Citations provided for previous applications in choice experiments or preference studies

Table 5.2. Sample characteristics of health care worker and community interview participants

	Number	Percentage
Health care workers	10	
Gender		
Male	3	30%
Female	7	70%
Mean age	37	
Profession		
Nurse	8	80%
Clinician*	2	20%
Total mean years of experience	12	
Mean years at current facility	3	
Community women	20	
Mean age	42	
Religion		
Christian	18	90%
Muslim	2	10%
Marital status		
Married	11	55%
Widowed	3	15%
Single/Divorced	6	30%
Education		
No formal schooling	6	30%
Attend some primary school	9	45%
Attended some secondary school	5	25%
Economic status		
Source of regular income	7	35%
Family owned house (compared to renting)	13	65%
Electricity	5	25%
Iron sheet roofing (compared to grass thatched)	11	55%

*Notes: *includes clinical officers, and resident physicians*

Table 5.3. Potential attributes and levels emerging from the interviews

Potential attribute	Lay terminology	Illustrative quote from health care worker and community interviews	Level included in DCE
Health information source, invitation to participate	Radio	"And many people are not literate, so we can't assume that they will be reading…but they have many have radios. So they can listen from the radio."	
		"Most of the time I hear about health issues on the radio."	
	Posters	"Because there are some posters that you can put at a health facility. Some posters that you can put even in the streets…There are some posters that just carry the message without the pictures and there are some posters that would carry sensitive pictures. If there is a poster of sensitive pictures, you put it on a place within the hospital setup."	
	Health surveillance assistant (HSA)	"In the communities we have health surveillance assistants…they are given the right information to disseminate…the basic information we want them to give to the community."	
	Community health meeting	"For home based care…those meetings they talk about health issues especially on HIV."	
		"Sometimes we also learn at church, doctors came to teach us."	
	Health talks in waiting area	"When they are giving the health talk they explain that maybe because the disease starts differently [in] others…they just have a lump."	Health talk in waiting area
Type of facility	Private	"Because at private when you, go you pay. When you receive treatment you get cured. But also when you go to government hospital you get cured and it's free treatment. So the best one is government hospital."	
	Government	"When I go to a government hospital I receive proper treatment. When you go to a private hospital they just tell you to go after they have given you medication. They just want money."	
Health infrastructure	Medication availability	"Sometimes when you go to the hospital they tell you that they have no medication. So you then have to buy the medication. You buy it at the pharmacy."	
	Proper resources	"If the resources are not there: the theatre may be out of gauze, the drips are not well sterilized or they are not sterilized at all because the sterilizer, is not functioning. They go back [home]."	

	Staffing shortages	"It depends if there is staff, then that's fine. But you know with this crisis of human resource, our setup, it also becomes a challenge."	
Perceived quality	How they greet me, provider interactions	"It is how they welcome us. They receive us well." "Like, the attitudes of the medical personnel. Because if patients come to our hospitals, the way we handle them matters. And then these patients go to the village and then they tell the community there. You know, I visited such such a hospital. And then the way they handled me whether it was bad or good. Then that you know, will make these other friends of theirs to either visit this hospital or not to visit this hospital."	
	Queues and wait time	"Because when I go to a government hospital, it is difficult for me to get treatment. For them to treat us, it takes long." "So aaah those patients who are referred from private clinics, they come here and discover how long the waiting list is, and then kind of get demotivated about it… when they get into the hospital most times they find a very long queue."	
Distance to facility	How long it takes to get there	"I cannot tell the distance because we get transport…so maybe 30 minutes."	Less than 1 hour
		"Aah, on minibus, it doesn't take very long. Because a minibus is a minibus. Really. But from my place, to where I take the minibus (where she gets on the minibus) it is a little bit far. It takes me about 45 minutes from my place to where I take the min bus." "It's one and a half hours, it's not very far, it's not far because even a child walk to get there."	1-2 hours
		"Eee…the district one, to travel by foot, you can start at as early as 5 o'clock if you walk very quickly, at around 8 you have reached at the hospital."	2+ hours
Transportation	Transport	"Most of the times when am going to the hospital, I walk because of little [financial] assistance. Maybe if am lucky that means a bicycle. If it can be possible that I can be taken on a bicycle (hiring someone to let her ride along)." "We also walk to [health clinic] but because the distance is long, we reach there late. When we have money for transport, we take a minibus."	
Services provided	Common things	"I like the big government hospital - it's where I like to go. To me it's where I see that I find assistance. And all the specialists are there."	

	Specialty care	"Bigger hospitals are important, but it depends on the sickness. If my sickness…is serious, I can go to receive treatment at the bigger hospitals…they give us better treatment."	
	Combined services	"I think it's the same as we say, "Come for baby checkup"…Then I think it would be better if we included the breast [exam]. We should not do only one. We should combine."	
Health encounter; point of entry	Under 5 (Child health checkups)	"We go lots for our children to be weighed because they have just started…it's daily at [health clinic] so we don't like to delay we will like our child to continue and receive injections."	Under 5 child checkup
	Family planning	"They are told at an earlier stage to be examining their breasts. Because in under five or family planning they give talks - health talks about self-breast examination." "If I had a breast problem that means maybe I would go to family planning."	Family planning
	Antenatal care	"What I know through learning some other times when we go for antenatal visits when you are pregnant, they were just telling us most of the time when you wake up, maybe you should be laying on your back and be rubbing your breasts, going round. If you feel a lump or pain you should rush to the hospital."	
	Cervical cancer screening	"To do two screenings, for the breast and for the VIA. Then, it will be much easier for the patient, I mean for the client, because she comes for VIA but at the same time her breasts are examined for breast cancer. Rather than her going home and coming back again another day for this other examination."	Cervical cancer screening
Type of provider	Health surveillance assistants (HSA)	"Sometimes she (HSA) reminds me: You should not forget to go to the hospital. I feel very free with this woman."	HSA
	Medical assistants	"The health centers are managed mostly by a medical assistant and then, so they have a lot of work to do." "So sometimes the medical assistants don't know much about the epidemiology of some of these conditions. They are able to pick out that this is a breast lump or what but then sometimes they don't just see...they just don't just see the urgency in certain situations."	
	Doctors	"Because we meet with doctors who are experts in everything."	Doctor

	Nurses	"There are other nurses who give proper treatment."	
Gender of provider	Female	"I would choose a woman because we are of the same nature."	Female
	Male	"I can choose a male health worker…For example…my first child, I was assisted by a male health worker to deliver it. I did not see any difference. The only difference was that the female health worker was just yelling. So the male health worker just said that he would assist me…he did not yell at me at all."	Male
Privacy	Feeling shy	"It's not a shameful thing. I don't feel shy to take off my clothes for a doctor. Because I say that they should see me."	
		"You have to hide them with a screen, so they are not seen by all the other people. There are no rooms; it is just open. So sometimes there are screens in between the beds, so we put another screen just to hide the front of it."	
Detection method	Get checked (CBE)	"It would catch as many as possible so we would miss less of these breast lumps and breast problems."	Clinical breast exam (CBE)
	Teach/learn how to check (BSE instruction)	"You can improve on health education. That means you can give talks starting from the community up to a health care facility. In the communities…we can…teach women in the villages to do self-breast examination."	Breast health awareness education and BSE
	Combination	"Yeah since we are in a setting where people are on queues waiting for so long sitting there so bored someone could just...someone like a nurse could just give them a health talk when they are in the sitting area…they will not be resisting when we suggest to them to do the breast exam at opportunity time like those, for as example if they come for the family planning clinic."	Both CBE and breast health awareness with BSE

Notes: DCE, discrete choice experiment; HSA, health surveillance assistant; CBE, clinical breast exam; BSE, breast self-exam

Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel 1-2 hours by foot	You travel less than 1 hour by foot
Your child has a health check	You go for a family planning visit
You meet with a doctor	You meet with a HSA
The health worker assisting you is a man	The health worker assisting you is a woman
You can have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose? Setting A or Setting B?

Figure 5.1. Example choice scenario in discrete choice experiment

CHAPTER 6: BREAST CANCER KNOWLEDGE, BELIEFS, AND PREFERENCES IN MALAWI: IMPLICATIONS FOR EARLY DETECTION INTERVENTIONS FROM A DISCRETE CHOICE EXPERIMENT

Introduction

Breast cancer is a growing public health problem in Africa and is currently the leading cause of female cancer death (1). The high mortality rates are likely due to large proportions of women being diagnosed with advanced disease and a scarcity of screening, diagnostic, or treatment services (34, 42). Increased awareness of the disease, common signs and symptoms, and available detection strategies is essential to increase early diagnosis and improve outcomes. This is a particular need given that breast cancer awareness and knowledge in Africa are generally low, especially in rural areas (34, 149-151).

Previous studies from African countries have shown that cultural and religious beliefs, competing health needs, and low socioeconomic status are associated with low breast cancer knowledge and poor help-seeking behaviors (3, 33). However, previous studies investigated mammography knowledge and behaviors (50, 152) or surveyed health workers or medical students (56, 153, 154), and few assessed breast cancer knowledge and practices within the general population (5, 6, 51, 155). Additionally, local social contextual factors may influence breast cancer knowledge and beliefs differently in various populations, and country-specific data are therefore needed due to differences in health system resources and specific cultural nuances.

In Malawi, one of the most resource-limited countries in the world, current reproductive health guidelines recommend promoting breast health awareness, including breast self-exam (BSE) and annual clinical breast exams (CBEs) (79). International organizations support these strategies as resource-appropriate options for early detection due to the lack of human and financial resources required for mammography (34, 42). Despite the potential for these strategies to address the increasing breast cancer burden, little is known about breast cancer knowledge and early detection behaviors in Malawi. In order to develop culturally appropriate, sustainable public health interventions, it is imperative to understand what

women know and value about breast cancer early detection. To our knowledge, no studies have employed a discrete choice experiment (DCE) to identify breast cancer early detection preferences in Africa.

The objective of this study was to explore knowledge, beliefs, behaviors, and preferences about breast cancer and early detection among Malawian women. Specifically we aimed to identify factors associated with breast cancer knowledge, beliefs that influence behaviors, and the most important characteristics of detection interventions.

Methods

Study setting

This study was conducted in Lilongwe district in the central region of Malawi. The district is divided into two main sections including Lilongwe City, the capital, and the surrounding rural Traditional Authority areas of Lilongwe. Lilongwe City is one of four major urban areas in the country, and is divided into 56 districts including many transitioning peri-urban residential areas. The estimated population for the entire district is over 1.35 million people (68).

The tiered hospital system provides free care through local health centers, district hospitals, and central hospitals. The central hospital for the region is in Lilongwe City and is one of two facilities in the country where chemotherapy is available for breast cancer patients. There is no functioning mammography equipment in the public hospital; however, mammography is available at one private clinic for approximately US$150.

Study design

We considered Lilongwe City and the rural section of the district separately and sampled residential districts in proportion to the female population size; industrial districts were excluded. We randomly selected geographic coordinates within the residential area boundaries using ZMaps (zonums.com). We confirmed whether coordinates landed on structures with ZMaps satellite imagery, and exported universal transverse Mercator (UTM) coordinates. The UTM coordinates served as a starting point for identifying survey respondents. Fieldworkers used handheld Garmin global positioning system (GPS) devices to locate the starting coordinate and approached the house closest to the coordinate to

assess eligibility. To be eligible, women had to be aged 18 years or older and able to provide informed consent; non-Malawian tourists and diplomats were not eligible. Because breast cancer risk increases with age, fieldworkers requested to interview the oldest woman of the house if she was available. After a successful interview, fieldworkers went to the third nearest house to conduct the next interview. If the initial attempt was unsuccessful, the next closest household was approached. Three interviews were conducted for each coordinate.

This study was approved by University of North Carolina Institutional Review Board and the Malawian National Health Service Research Committee.

Data collection

Data were collected in the local language (Chichewa) via interviewer-administered surveys between July and August 2014. Fieldworkers entered survey responses into Open Data Kit (opendatakit.org) Collect on tablet computers, and data were uploaded daily after returning from the field. Adherence to study protocol was assessed throughout the data collection period by the principal investigator and/or field supervisor by observing interviews and conducting quality assurance of uploaded data.

Measures

The survey instrument included questions on knowledge, beliefs, and behaviors regarding breast cancer, BSE, CBE, and demographic characteristics. Survey questions were conceptually derived from the Health Belief Model (HBM), which posits that multiple factors influence the adoption of health behaviors including perceived threat of a health condition, perceived benefits and barriers of a health action, cues to action, and self-efficacy (156, 157). However, traditional instruments measuring HBM variables, such as versions of Champion's breast cancer beliefs measures (98, 99, 158), have not been validated in African populations, nor do they assess CBE beliefs. Therefore, we adapted scales for Malawian women and to match currently available early detection strategies recommended by Malawian health guidelines.

Among the women with some knowledge of breast cancer, we assessed perceived threat of breast cancer based on two relevant items from Champion's susceptibility scale (98, 99). During pre-testing women had difficulty with repeated questions using different time frames; thus, we only evaluated

the lifetime risk perception. We were able to translate three items from the Champion fear construct (99), but other terms were translated as similar words. For example, 'jittery', 'uneasy', and 'anxious' were the same as 'nervous'; 'upset' and 'depressed' were also translated similarly. Therefore, we only included 'scared', 'nervous', and 'upset' in the survey. Select items from the benefits, barriers, and self-efficacy Champion scales were also assessed for BSE and CBE if women were aware of the detection behaviors. Fatalism measures were derived from Powe's scale to determine hopelessness and the inevitability of death associated with a cancer diagnosis (159).

We were not able to use Likert-scale response options because of difficulties in translating meaningful response terms, which was problematic in pre-testing. Additionally, local experts recommended using simple response options due to low education levels and interpretation problems. Thus we used "yes," "no," or "don't know" responses for nearly all of the questions. To elicit women's preferences about early detection strategies, we designed a DCE for the final section of the survey.

Discrete choice experiment

A DCE is a survey method commonly used to elicit preferences for health services (89, 160). This approach is based on the assumption that a health service or intervention can be broken down into separate attributes, or characteristics, and the total utility gained from using that service is a function of the individual utilities of the attributes (92). This method involves presenting respondents with hypothetical scenarios and forcing them to state which option they would prefer to reveal their preferences (91). This technique is grounded in random utility theory, meaning respondents should choose the scenario which produces the highest utility (85). Individual-level preference estimates can be used to calculate utilities for each attribute-level. Estimation models can also determine the relative importance of attributes. Identifying which attributes of cancer detection services women value the most will help inform future intervention designs that are more likely to be acceptable.

We followed the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) guidelines to select and test five attributes (85). We have previously described the development of the DCE where we conducted a literature review, individual interviews, and cognitive testing to specify attributes and levels and to determine the optimal design (Chapter 5). The final attributes included in the DCE were travel time (<1 hour by foot, 1-2 hours by foot, >2 hours by foot), health encounter where

intervention would be offered (health talk in facility waiting area, community health gathering, cervical cancer screening, family planning clinic, or child under five clinic), the type of health worker conducting the intervention (doctor or health surveillance assistant [HSA]), the gender of the health worker, and the early detection strategy offered (Breast health awareness with BSE, CBE, or combined breast health awareness and CBE).

Two native study team members familiar with breast cancer in Malawi independently translated the DCE into Chichewa, compared results and agreed upon a common translation. The Chichewa DCE was back translated by an independent translator who had no previous experience with the tool. After comparing the back translation to the original English version, the three translators discussed differences and revised the Chichewa translation to be conceptually relevant. Minor modifications were made after pre-testing the DCE.

Using a full factorial design including all possible combinations of the levels and attributes was not feasible; therefore, we used Sawtooth Software version 8 (Sequim, Washington) to create an efficient and balanced fractional factorial design with 144 hypothetical profiles. Pre-testing suggested that 16 choice tasks were cognitively burdensome and not manageable; thus, we blocked the design into 12 different versions of 9 tasks for the cards, including one practice task where the same choice set appeared for every respondent. Each choice card presented two early detection opportunities with images and descriptions of both profiles. During pre-testing we explored multiple choice formats and determined that a multiple choice design complicated the understanding and administration of the survey. We used a binary choice format because a large proportion of the target population was expected to have limited education and low literacy levels.

Statistical analyses

Descriptive statistics and knowledge, beliefs, and behavior responses were analyzed in Stata version 13. We used multivariate logistic regression to identify predictors of knowledge. Knowledge scores were calculated for all women who were aware of breast cancer. The score was calculated by summing the number of correct responses for signs, risk factors, and treatment options; "don't know" responses were scored as incorrect. We examined t-tests comparing the mean scores and Chi-squared

tests of a dichotomous knowledge variable (based on the median score) by sample characteristics to identify factors associated with higher knowledge of breast cancer.

The DCE results were analyzed using the hierarchical Bayesian (HB) module for choice-based conjoint (CBC) analysis in Sawtooth software. The CBC/HB approach estimates preferences across and within respondents, which means this type of model can determine whether preference heterogeneity exists and can also estimate individual-level preferences (102). At the individual level (the lower level) a multinomial logit model estimates the probabilities of choosing particular alternatives. The Bayesian approach allows us to compare and update an individual's estimates of choice probabilities based on the means and covariances of a normal distribution of preferences from other respondents (the higher-level). Sawtooth uses a Monte Carlo Markov Chain to estimate parameters through an iterative process, which means estimates from the previous iteration are used to determine the estimates of the next iteration until the model converges at the right distributions of the parameters (103). Then the individual's utility estimates of each attribute level are averaged after 10,000 random draws. The CBC/HB approach also estimates importance scores for the attributes based on each individual's utilities; these scores are used to calculate average importances of attributes across all respondents.

The results are presented as raw utility estimates and can be interpreted as the attractiveness of each level within the attribute, with higher numbers indicating more attractive options (161). We used effects coding such that the last level within each attribute was not included in the model, but was estimated as the negative sum of the other attribute levels.

Results

Study characteristics

Of 262 women from the Lilongwe district approached to participate in the survey, 22 (8%) were ineligible and 27 (10%) refused. We recruited 213 women to participate; these women agreed and gave consent to be interviewed for the survey. Of these, the mean age was 38 years, 82% were Christian, 83% were married, and 64% had no formal schooling or only a primary education. More than half of the sample owned the home they lived in and 79% had iron sheet roofing, but only 28% had electricity and 38% had a water tap at their house.

Breast cancer knowledge

Less than half of the sample (44%) was aware of breast cancer at the time of the interview, indicating they had never before heard of breast cancer. Most women who were aware of breast cancer reported that they learned about the disease from a health worker (39%) or a family member or friend (38%). Other sources of information included the radio (19%), health talks at a clinic (8%), and community health gatherings (4%).

In bivariate analyses (Table 6.1), women who were aware of breast cancer were more likely to have higher education levels ($p=0.002$) and to have electricity ($p<0.001$), a water tap ($p<0.001$), and iron sheet roofing ($p=0.008$) at their homes. Women who had a physical exam in the past six months (39% versus 26%, $p=0.04$) and those who had been tested for HIV (87% versus 76%, $p<0.03$) were more likely to be aware of breast cancer.

Those who knew someone with cancer were much more likely to be aware of breast cancer (48% versus 18% $p<0.001$). Among women who had prior cancer-related experiences (67), most had a family member who was diagnosed with cancer (57% including parents, children, spouse, or other relative), followed by a friend (28%), and neighbor (5%). Breast cancer awareness was positively correlated with BSE awareness ($p<0.001$) and CBE awareness ($p<0.001$).

In multivariate analyses, increasing age (adjusted odds ratio (AOR) 1.02, $p=0.04$), having electricity at home (AOR 3.38, $p=0.04$), and knowing someone with cancer (AOR 4.03, $p=0.04$) significantly increased the odds of breast cancer awareness.

We assessed breast cancer knowledge in more detail among those who were aware of breast cancer (Figure 6.1). Women were most knowledgeable about the signs/symptoms compared to treatment or risk factors (Table 6.2). Most women correctly identified a lump as a sign/symptom of breast cancer (80%), and although many women knew multiple signs/symptoms, 11% did not know any. Twenty-four percent did not know any correct risk factors, and many women had misconceptions about risk factors and causes. A majority thought storing a cell phone and money in a bra could increase the chances of developing breast cancer (64% and 61%, respectively), and 30% believed breast cancer was contagious. A majority (81%) knew that surgery to remove the breast was a form of treatment, but fewer women knew about chemotherapy and hormonal therapy.

The mean total score of knowledge was 9.92 out of 20 total correct responses (standard deviation 4.84), and the median score was 10. We observed few differences in the mean knowledge scores by sample characteristics. However, women who were aware of CBE were more knowledgeable about breast cancer (11.5 versus 8.9, p=0.01).

Beliefs

In general women had a varying levels of perceived threat of breast cancer (Table 3). Less than half of those who were aware (44%) believed they would develop breast cancer at some point in their lifetime. Even fewer women (37%) were concerned about their chances of developing breast cancer. Women with lower education levels and those without a water tap at their house were more likely to perceive breast cancer as a threat (p=0.006 and p=0.02, respectively). Fear of breast cancer was slightly more common among women aware of the disease. Summing the three point scale, the mean fear score was 2.15, with half of the respondents (47) agreeing with all 3 items. Women without a personal water tap at home had a heightened fear score compared to those with a personal tap (p=0.05). Just over half of the women aware of breast cancer (52%) agreed with at least one of the fatalistic statements about breast cancer diagnosis. Those with lower education levels (p<0.001), thatched roofs (p=0.01), without water taps (p<0.001), and not married (p=0.02) had more negative beliefs about breast cancer. Women unaware of BSE and CBE had stronger fatalistic beliefs about breast cancer (p=0.04 and p=0.05, respectively); there were no differences in perceived threat or fear by awareness of early detection behaviors.

Breast self-exam

Seventeen percent (36) of the full sample was aware of BSE. Most women learned about BSE from a doctor (14), a family member or friend (11), the radio (5), or a health talk (9). Among those who knew of the practice, 29 (81%) women thought performing regular self-exams would help find breast cancer early, and 13 (36%) thought it should be performed monthly. Twenty-four women (67%) reported doing a self-exam at least once and most did it monthly (54%). Of those, only a few noted barriers to performing BSE (Table 6.5); although 83% (20) indicated they knew how to do it, only 58% (14) were confident they could do it correctly.

Clinical breast exam

Twenty percent of the full sample (43/213) had heard of CBE. Doctors were the most common source of information about CBEs (23), followed by families or friends (13), the radio (4), health talk (4), a religious gathering (2), and television (1). Among those who were aware, most women thought CBEs helped find lumps early (39), decreased the chance of dying from breast cancer (40), and might help find lumps before a woman could feel it herself (37).

We explored potential barriers of having a CBE and found that not knowing where to go and transportation were the most common barriers (45% and 30%, respectively). Seven women (17%) thought a CBE was unnecessary because of lack of symptoms and four thought they had other problems that were more important than getting a CBE; only two women (5%) indicated they would be embarrassed about their body. Of the 29 women who had never before had a CBE, additional barriers were indicated, including CBE taking too much time (14%), being painful (14%), and having concerns about their husbands not approving (7%).

Few women (14) had ever received a clinical breast exam, half of which occurred within the past 12 months. Most women were examined by doctors (9) compared to nurses, and most had the exam at a private clinic (5) or the central hospital (4). We asked women about their experience; four thought the exam was embarrassing, four said it was uncomfortable, and two thought it was painful. Only two women said they were unwilling to have another CBE in the future, but did not provide a reason for declining the exam.

Interest and acceptability

All women were asked whether they would adopt the detection behavior if a health worker offered to teach them how to do BSE. Compared to women who were previously unaware of BSE, those who knew about the practice were more interested in conducting BSE if they were taught how to do so (100% versus 89%, p=0.05). Those who were not interested cited being too busy or too old to do BSE (3), being unable to do it (3), and that a clinician can do it more effectively (2) as reasons for declining. We also asked all women if they would accept a CBE if a health worker asked to do the exam. Ninety-six percent were willing to have a CBE. Four women said they would refuse because they were too old or not sick.

Before completing the DCE, we assessed women's interest in learning more about breast cancer and how they would like to get information. Ninety-seven percent (206) of the full sample was interested in getting additional information about breast cancer. Only one of the seven women who did not want more information provided a reason for her lack of interest; she thought she was too old so there was no need for her to learn more. The most commonly requested information source was a doctor (64%), community health worker (40%), radio messages (20%), seminar at church/school (15%) and health talk at health facility (15%).

Preferences regarding breast cancer detection services

We examined the proportion of times the attribute levels of the DCE were selected when they were presented. Not surprisingly, we found that the shortest travel time was selected more often than longer travel times ($p<0.01$). The community health meeting was chosen 60% of the times it appeared and was the most popular health encounter where the early detection intervention would take place ($p<0.01$). Doctors were preferred over HSAs and were selected 55% of the times they occurred. Although women favored female health workers, there were no significant differences for gender. The combined early detection intervention of CBE and learning about breast health awareness was selected most often when given the choice (58%, $p<0.01$).

There were no differences in preferences by breast cancer awareness. The only demographic variable affecting preferences was residence; and early detection strategy and time travel were significantly different. Compared to women living in rural areas, those who lived in urban areas were more likely to favor learning about breast health awareness and less likely to prefer having a CBE or both early detection strategies ($p<0.01$). Urban women were also more sensitive to travel time ($p<0.01$).

Estimated utilities

To determine which model fit the data best, we also performed multinomial logistic regression with and without interaction terms, which led to similar results as the initial model and only a slight improvement in model fit. We investigated differences by rural residence and ran the HB model with rural as a covariate, but did not observe significant differences in preferences after controlling for rural residence. Therefore, we report the HB model with no covariates (Table 6.4).

The utility levels estimated from the CBC/HB indicate that women valued having a breast exam, particularly if it was combined with breast health awareness. Interventions only providing education on breast health awareness were less popular. Respondents preferred shorter travel times compared to walking for multiple hours and favored female doctors. Women had strong preferences for having the early detection intervention available at a family planning clinic; early interventions offered at a community health meeting were also favored though not as strongly.

The mean importance scores indicate the comparative importance across the five attributes. The early detection strategy (27%), health encounter (24%), and travel time (21%), were the most important options. The gender (14%) and type of health worker (14%) were less important to women's decisions.

Discussion

The results of this study show that more than half of Malawian women were unaware of breast cancer and early detection strategies. Of the women who were aware of breast cancer, nearly half were not knowledgeable about signs/symptoms, risk factors, and treatment options. Local misconceptions about causes of breast cancer were commonly reported and few women exhibited behaviors in line with recommended early detection strategies within Malawi. Although most women did not have a high perceived threat of breast cancer, some were fearful of the disease. Few respondents had ever received a CBE or practiced BSE. The DCE findings demonstrate that women preferred a combination of early detection strategies being offered at family planning clinics that do not require long travel. To the best of our knowledge, this is the first study examining the knowledge about breast cancer and early detection among the general population in Malawi and the first DCE eliciting preferences for breast cancer early detection in Africa. These findings have several potential policy, clinical practice, and future research implications.

First, our results suggest that widespread public breast cancer education is needed to increase knowledge of the disease. Whereas some studies in African countries indicate relatively good awareness of breast cancer and poor knowledge of risk factors, our findings were similar to reports from more rural African populations showing low levels of awareness more generally (5, 150, 151). Compared to a recent study of urban Tanzanian women using outpatient services, a greater proportion of our sample was

aware of someone diagnosed with cancer, but had much lower levels of breast cancer knowledge (162). Nevertheless, in our study previous exposure to any type of cancer survivor played an important role in women's awareness of breast cancer, and many women learned about breast cancer from their social networks. Additionally because a large proportion were afraid of breast cancer, public health messages about the benefits of early detection could be enhanced by including current survivors from the community to increase awareness and promote survivability of breast cancer.

Our findings also suggest that in order to maximize participation in an early detection intervention, decision makers could encourage health workers to incorporate detection strategies into currently existing health services. Health workers were frequently mentioned as an information source for breast cancer, and many women interested in learning about breast cancer wanted education from a doctor or community health worker. Although the DCE results show that some women were interested in learning about breast health awareness, women were more interested in having the exam that just learning about how to do a BSE, which may reflect positive attitudes towards providers and medical care.

The results also indicate that convenience of early detection interventions is important. Travel time was an important attribute that influenced our sample's intervention choices and transportation was identified as a potential barrier to CBE, highlighting how structural barriers affect health behaviors and preferences. In prior research among Malawian breast cancer patients, we also found that structural barriers influenced delayed diagnosis and treatment (Chapter 4); transportation, costs of care, and access to providers have been reported in cancer care studies across Africa. This indicates that future early detection interventions should be conveniently located for women with minimal travel times, suggesting that services should be offered in lower-level clinics that are dispersed throughout urban and rural areas.

We also found that interventions offered during health talks in waiting areas, under five child clinics, and cervical cancer screening were not as popular. This may be due to the relevance and convenience of these services, a woman's age or stage of life, or awareness of cervical cancer screening. Studies from South Africa have reported challenges of combined breast and cervical cancer screening with mobile clinics and community health workers (142). Although women valued the education provided by the health worker, it did not affect screening uptake. Women in our study preferred having early

detection services at family planning clinics, which likely serve younger women with relatively low risk for breast cancer. However, this may have been a natural choice for women because physical exams are commonly provided at family planning clinics, thus they may be associated with preventive care. Additional research into the optimal package of women's cancer detection services for certain groups of women is needed.

Based on qualitative findings from the DCE development, we expected health worker gender to be an important characteristic of early detection strategies, but these findings suggest it is not as important as structural or process characteristics of the intervention. Thus, it seems as though women value receiving a clinical exam and are willing to accept any professional medical help with less concern about the health worker type or gender. This may also be due to traditional paternalistic social norms regarding health workers and women not feeling like they have a choice to be assisted by a female.

This study has some limitations, including that our sample was primarily drawn from one district in Malawi and may not be generalizable to other settings because knowledge and preferences may vary across countries. However, Lilongwe is the largest city in Malawi and has a diverse population in terms of tribal background, religion, and education levels. Another limitation is that we were unable to use a validated HBM scale, but we adapted items from prior studies to assess similar constructs. Women's preferences for participating in early detection strategies are likely different in various countries and may be influenced by cultural, religious, or socioeconomic factors. Additionally, paternalistic tendencies and strong cultural pressures to follow health worker recommendations may influence women's willingness to accept services; however, a large proportion of the sample indicated they were interested in both early detection strategies. Finally, limited prior knowledge of breast cancer and little experience with early detection behaviors may mean that our sample values attributes differently than women more aware of breast cancer and detection services. The evidence for the effect of experience on preference patterns is mixed; some studies indicate preferences are generally consistent with both experienced and naïve respondents, whereas other studies have observed clear differences in preferences by experience (163, 164). Although we did not observe differences by breast cancer awareness, additional research on this topic is needed, especially given the growing burden of cancer in Africa and generally low levels of awareness. In future research, we plan to explore heterogeneity in preferences by segmenting the DCE

respondents into subgroups and modelling the optimal intervention packages for different groups of women.

Conclusions

Our findings showed that interventions to address low levels of breast cancer knowledge and early detection behaviors are needed. Overall women were interested in early detection strategies, but valued the convenience of detection interventions. Future interventions may be more successful if they provide both breast health awareness and clinical services and are designed to address barriers to care such as travel and transportation. Improving knowledge and increasing access to early detection strategies through existing health services have potential to make a significant impact on breast health outcomes.

Figure 6.1 Sub-groups of survey sample

Notes: BSE, breast self-exam; CBE, clinical breast exam

Table 6.1. Survey sample characteristics

	Not aware of breast cancer N = 119 (%)	Aware of breast cancer N = 94	Total N = 213	p-value
Age *mean, standard deviation*	37.0 (13.8)	39.6 (15.1)	38.1 (14.4)	0.10
Religion				0.43
Christian	95 (79.8)	80 (85.1)	175 (82.2)	
Muslim	12 (10.1)	9 (9.6)	21 (9.9)	
No religion	12 (10.1)	5 (5.3)	17 (8.0)	
Married	94 (79.0)	83 (88.3)	177 (83.1)	0.07
Education level				0.002
No formal school	28 (23.5)	14 (14.9)	42 (19.7)	
Primary	60 (50.4)	34 (36.2)	94 (44.1)	
Secondary	25 (21.0)	29 (30.9)	54 (25.4)	
Completed secondary	6 (5.0)	17 (18.1)	23 (10.8)	
Rural	59 (49.9)	36 (37.9)	95 (44.6)	0.10
Economic characteristics				
Home ownership	77 (64.7)	50 (53.2)	127 (59.6)	0.09
Electricity	19 (16.0)	41 (43.6)	60 (28.2)	<0.001
Water tap access	31 (26.1)	49 (52.1)	80 (37.6)	<0.001
Roofing	86 (72.3)	82 (87.2)	168 (78.9)	0.008
Health service indicators				
Physical exam within past 6 months	31 (26.1)	37 (39.4)	68 (31.9)	0.04
Tested for HIV	90 (75.6)	82 (87.2)	172 (80.8)	0.03
Cancer awareness outcomes				
Aware of BSE	2 (1.7)	34 (36.2)	36 (16.9)	<0.001
Aware of CBE	6 (5.0)	37 (39.4)	43 (20.2)	<0.001
Peer cancer-related experience	22 (18.5)	45 (47.9)	67 (31.5)	<0.001

Notes: HIV, human immunodeficiency virus; BSE, breast self-exam; CBE, clinical breast exam

Table 6.2. Knowledge among women aware of breast cancer* (n=94)

Signs and symptoms	n[†] (%)	Risk factors	n[†] (%)	Treatment options	n[†] (%)	Total
Lump	75 (80)	Family history	45 (48)	Surgery	76 (81)	
Breast pain	67 (71)	Never having children	26 (28)	Chemotherapy	23 (24)	
Nipple discharge	63 (67)	First delivery after 30 years old	31 (33)	Hormonal therapy	25 (27)	
Nipple discoloration	60 (64)	Short breast feeding duration	27 (29)			
Skin retraction	58 (62)	Age	28 (30)			
Breast discoloration	67 (71)	Overweight	19 (20)			
Change in shape	65 (69)	High fat diet	24 (25)			
Itchy nipple	52 (55)	Alcohol	49 (52)			
Dimpling (peau d'orange)	53 (56)					
Mean number correct (sd)	5.9 (3.3)		2.6 (2.4)		1.3 (0.9)	9.9 (4.8)
Mean percentage score (sd)	66.2% (37.0)		33.1% (30.5)		44.0% (31.7)	49.6% (24.2)

Local misconceptions about causes and treatment of breast cancer

		Clogged milk	39 (41)	Herbal medicine	14 (15)	
		Hybrid chickens	42 (45)	Prayers	44 (47)	
		Storing cell phone in bra	60 (64)	Fellowships, healing revivals	28 (30)	
		Keeping money in bra	57 (61)			
		Contagious	28 (30)			

Notes: *includes 94 women aware of breast cancer
† Number of women who correctly identified each response
sd, standard deviation

Table 6.3. Breast cancer beliefs among Malawian women aware of breast cancer (n = 94)

	n†	%
Threat		
Do you think you will get breast cancer in the future?	41	43.6
Are you worried about your chances of developing breast cancer in your life-time?	35	37.2
Mean score (sd)	0.81	(0.88)
Fear		
When you think about breast cancer, do you feel scared?	57	60.6
When you think about breast cancer, do you feel nervous?	72	76.6
When you think about breast cancer, do you feel upset?	73	77.7
Mean score (sd)	2.15	(1.04)
Fatalism		
Do you believe cancer will kill most people who get it?	45	47.9
Do you believe if someone gets cancer, it doesn't matter when they find out about it, they will still die from it?	1	1.1
Do you believe if someone has cancer, it is already too late to do anything about it?	36	38.3
Mean score (sd)	0.86	(0.90)

Notes: *includes 94 women aware of breast cancer
† Number of women who responded yes
sd, standard deviation

Table 6.4. Raw utility estimates from discrete choice experiment (N = 213)

Attributes	Levels	Mean utility	95% Confidence interval	Mean attribute importance	95% Confidence interval
Travel time				21.17	19.53-22.80
	<1 hour by foot	0.84	0.69 – 0.99		
	1-2 hours by foot	-0.06	-0.17 – 0.05		
	>2 hours by foot	-0.78	-0.93 – -0.63		
Health encounter where intervention is available				24.32	23.18-25.47
	Health talk in facility waiting area	-0.11	-0.27 – 0.04		
	Community health gathering	0.04	-0.19 – 0.27		
	Cervical cancer screening	-0.13	-0.29 – 0.03		
	Family planning clinic	0.38	0.21 – 0. 56		
	Child under 5 clinic	-0.19	-0.37 – 0.003		
Health worker				13.70	12.26-15.15
	Doctor	0.52	0.41 – 0.62		
	Health surveillance assistant	-0.52	-0.62 – -0.41		
Gender of health worker				14.24	12.78-16.69
	Male	-0.20	-0.31 – -0.10		
	Female	0.20	0.10 – 0.31		
Early detection strategy				26.57	24.83-28.30
	Breast health awareness	-1.08	-1.23 – -0.93		
	Clinical breast exam	0.14	-0.02 – 0.05		
	Breast health awareness and clinical breast exam	0.94	0.79 – 1.09		

Table 6.5. Perceptions among women exhibiting early detection behaviors

	n	%
Performed BSE	24	
BSE benefits*		
When you perform a BSE, do you feel good about yourself?	22	91.7
Do you perform BSE to have peace of mind?	22	91.7
Do you think if you find a lump through BSE, treatment may not be as bad?	16	66.7
BSE barriers*		
Are you afraid to do BSE because you might find out something is wrong?	2	8.3
Do you think BSE takes too much time?	2	8.3
Do you have other problems more important than doing BSE?	1	4.2
BSE motivation*		
Do you perform BSE because a doctor told you to?	20	83.3
BSE self-efficacy*		
Do you know how to perform BSE?	20	83.3
Are you confident that you can perform BSE correctly?	14	58.3
Received CBE	14	
CBE benefits†		
When you get a CBE, do you feel good about yourself?	12	85.7
When you get a CBE, do you worry less about cancer?	12	85.7
Did you get a CBE to have peace of mind?	13	92.9
CBE barriers†		
Are you afraid to have a CBE because you might find out something is wrong?	3	21.4
Do you have other problems more important than getting a CBE?	3	21.4
CBE motivation†		
Did you get a CBE because a doctor told you to?	9	64.3
CBE self-efficacy†		
Do you know where to go to get a CBE?	12	85.7
Do you think it would be difficult to get transportation to have a CBE?	3	21.4

Notes: *among 24 women who reported ever practicing BSE
† among 14 women who reported ever receiving CBE

CHAPTER 7: CONCLUSIONS AND IMPLICATIONS FOR POLICY, PRACTICE, AND RESEARCH

Summary of findings

This dissertation makes a significant contribution to the literature and has implications for policy, practice, and future research. This is the first study to develop a framework for understanding breast cancer delay in SSA, which highlights the importance of local social and cultural influences on delay and identifies opportunities to improve access to care and areas for public health interventions. This is also the first breast cancer detection DCE developed and administered in Africa, where few DCEs have been employed. Finally, the results of the survey provide important data on public awareness of breast cancer, which had not been previously assessed.

The results of the patient interviews indicated that many breast cancer patients experienced long delays between noticing a symptom, deciding to seek care, reaching the health facility, getting diagnosed, and initiating treatment. Patients were largely unaware of breast cancer and did not immediately consider their symptoms to be serious, which delayed the decision to seek help. However, as symptoms progressed, women sought advice and were strongly influenced by social networks, which helped some women decide to seek medical care faster, but also caused delays for others who pursued traditional remedies. Cultural attitudes about the importance of testing, benefits of getting to the hospital quickly, and trust in providers also influenced women's health-seeking behaviors. Socioeconomic position, distance to the facility, and health care system factors were commonly mentioned as challenges in reaching health facilities and accessing cancer care. These findings highlight the need for increasing awareness of breast cancer signs and symptoms in Malawi and implementing policies to reduce barriers to timely and appropriate care.

The results of the provider and community interviews informed the development of the preference assessment tool (Aim 2). Themes that emerged from interviews provided critical information about breast

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cancer detection services, specifically, that breast cancer detection interventions should be integrated into other health services because screening asymptomatic women may not be practical as a stand-alone service. Based on participants' responses the final attributes of the choice experiment included travel time, type of health encounter (e.g., cervical cancer screening, family planning), health worker type (e.g., doctor, HSA) and gender, and breast cancer early detection strategy (e.g., breast health awareness, CBE). Cognitive testing confirmed the acceptability of the final attributes, comprehension of choice tasks, and women's abilities to make tradeoffs. The results of Aim 2 determined that applying a DCE for breast cancer early detection was feasible with appropriate tailoring for a low-income, low-literacy African setting.

Results from Aim 3 indicated that less than half of the survey sample was aware of breast cancer. Among those who were aware, women were more knowledgeable about symptoms than treatment options or risk factors. More women erroneously believed that non-risk factors (e.g., storing phone or money in a bra) contributed to breast cancer occurrence than established risk factors. DCE results indicated that the detection strategy offered (breast health awareness, CBE, or both) was the most important attribute of an early detection intervention. This suggests that the services provided during the health encounter were influential in women's choices between interventions, and health education alone may not be as attractive as clinical exams. The type of health encounter where services were available and travel time were also important intervention characteristics. Malawian women had strong preferences for a shorter travel time to reach a facility and exhibited preferences to have an intervention available at family planning clinics or in a community health setting. The findings suggest potential benefits from early detection interventions tailored to women's preferences, including breast health education and clinical breast exams promoted in convenient settings.

Implications for policy and practice

These three analyses suggested that Malawian women have poor knowledge of breast cancer, but are eager to learn about early detection. In general, women understood the benefits of early diagnosis and early treatment, but did not know signs/symptoms of breast cancer or how breast cancer was detected. Misconceptions about causes of breast cancer were also common, many women were afraid of the disease, and some believed the disease was always fatal. Educating the general public on symptoms

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and risk factors is essential to improve early detection in Malawi, and integrating health beliefs into public health messages may help address misconceptions and improve breast cancer knowledge and behaviors in Malawi. Additionally, many women in this study knew about breast cancer because of direct or indirect connections with a cancer patient; therefore, including cancer survivors in education programs may be an effective way to reach women and disseminate health messages. Engaging survivors may also reinforce concepts that breast cancer can be effectively treated and often cured in Malawi, which would promote positive attitudes toward cancer help-seeking and may reduce fears of cancer diagnosis among the public. We also found that socioeconomic status (i.e., electricity at home residence) was associated with breast cancer awareness, suggesting that public health messages must cross socioeconomic strata in order to reach more women. Community health workers and radio messages may be important ways of reaching women in remote areas and were popular sources of health information among this sample. Future research could also explore the potential to use text messages as a health promotion tool, which has been successful in other African settings because of wide cell phone coverage. However, breast awareness campaigns must be implemented with caution so as not to overwhelm the health system with women seeking help for minor benign conditions. Until Malawi has additional infrastructure and human resources, public health education programs should focus on encouraging women with symptoms suggestive of breast cancer to seek medical care quickly.

Efforts to increase public awareness of breast cancer must also be complemented with health care provider and system-level changes. Ensuring local health care facilities are equipped with trained providers and protocols to diagnose and evaluate suspected breast cancer is a critical next step for Malawi. Specifically, primary care providers need training to improve their knowledge of breast cancer, signs/symptoms, and early detection strategies. Provider delays were commonly mentioned in patient interviews, and the providers we interviewed also noted they would benefit from a refresher course on breast cancer. Results from this study could be used to inform the Malawian Ministry of Health about the need to train primary care providers at local health centers and district hospitals on breast cancer signs/symptoms, risk factors, and clinical breast exams. Interventions to educate health providers may help reduce medical errors and misdiagnoses, identify suspected cases earlier, and expedite the referral process.

Patients also faced challenges reaching health facilities due to long distances and high transportation costs, which highlights the need to expand services at local health centers to increase the availability of detection and diagnostic services. Additionally, DCE results indicated that convenience was an important determinant of early detection interventions, thus services should be widely distributed throughout the health system to make them more accessible in both rural and urban areas and to reduce transportation barriers.

This study also identified gaps in the health system once patients reach the health facility for diagnostic evaluation. Expanding and improving diagnostic services, such as imaging and pathology, may also improve turnaround times and allow women to receive diagnostic confirmation and start treatment sooner. Patients may also benefit from additional support services at the hospital to ensure that they understand their diagnosis and treatment plan, and return for additional evaluations or follow-up appointments as recommended. Counselling and education with a navigator may help address this need, prevent delays or loss to follow-up, and improve adherence.

As Malawi's capacity to provide cancer care increases, breast programs could expand from focusing primarily on symptomatic disease to efforts aimed at identifying asymptomatic cancers. Results from both studies to develop and employ the DCE indicated that women prefer to have early detection services available at health encounters they already frequently use, such as family planning and community health meetings. However, providing early detection at additional facilities would be necessary so as not to limit access to the service and only target women of younger ages who have a lower risk of breast cancer. Integrating early detection into a comprehensive women's health visit at commonly used health clinics may be a way to build the health system and increase uptake particularly for asymptomatic screening. Bundling services would promote comprehensive health care by diagnosing and treating breast cancer early while also addressing other health issues, but should be done with care in light of current resource constraints.

Limitations

Although this dissertation makes several contributions to the breast cancer literature, limitations must be noted. Except for the provider interviews, the qualitative components of this dissertation were

conducted in Chichewa and translated into English. Translation errors may have occurred and some nuances of the cultural expressions may have been lost; however, we used a systematic approach and multiple translators to ensure translations were accurate and conceptually relevant. This dissertation was designed to assess local social and cultural factors that influence breast cancer knowledge and behaviors among Malawians, and therefore, it may not be generalizable outside Malawi. Although we purposefully recruited patients and providers with a range of experiences, these interview samples were based in urban Lilongwe City and may not be representative of perspectives from other facilities, especially more rural or peripheral health centers. However, half of the patients we interviewed travelled from outside of the district to get care at KCH. Additionally, we recruited community interview and survey participants from Lilongwe district, the largest of 28 districts in Malawi, and included may non-urban participants as well as using a random sampling approach to strengthen external validity of the results. However, our results could likely be strengthened with a larger and more diverse sample from additional districts or regions of Malawi.

The nature of this study required patients to recall previous memories and events, which may bias the results. However, many of the attitudes patients expressed about testing, early detection, and presenting to the hospital aligned with the community participants' responses. This suggests that women have positive attitudes about seeking medical care in general and may have similar attitudes about cancer detection once they are aware of cancer.

Regarding the quantitative survey, we were unable to validate a previously tested knowledge and beliefs instrument. Therefore, we developed our own questionnaire because no previously existing measurement tools had been translated into Chichewa or validated in a Malawian population. However, we modified commonly used formats and adapted items from validated scales for the target population; we also added important concepts that emerged from Aim 1 interviews (e.g., commonly reported causes of breast cancer) to keep the survey questions relevant to the Malawian context. Additionally, because of adjustments to the response options and the small number of women who were aware of breast cancer, CBE, and BSE, we were unable to assess HBM scale validity and reliability.

Future research directions

Future research should prioritize defining a locally-relevant algorithm for breast cancer symptoms that health care providers can use when deciding whether or not to refer patients for additional evaluation. This algorithm could be included with national guidelines for reproductive health and promoted across all levels of health care facilities in Malawi. Implementation of a breast cancer triage algorithm would allow providers to assess the severity of a patient's symptoms and determine who should be referred more easily. For example, primary care providers at lower-level facilities could use a checklist of breast symptoms to help identify and triage women after an initial CBE. Additionally it may be helpful to create and distribute a health passport stamp for CBE results and symptoms similar to what Malawi uses for cervical cancer screening. An algorithm would be enhanced by developing a predictive model based on documented symptoms and outcomes among current patients and participants from an ongoing screening pilot study. High-quality data on breast cancer patients' clinical presentation, stage, treatment, and outcomes are also needed to develop an appropriate algorithm. Data of this nature would also allow us to better quantify the impact of delay on cancer outcomes.

In terms of future early detection and screening studies, because mammography may not be feasible on a large scale in Malawi, a study evaluating CBE as a detection tool is a reasonable next step. Although the DCE results suggested women preferred doctors over HSAs, the provider type and gender were somewhat less important attributes of the intervention given the range of levels tested; therefore, it may be feasible and acceptable to implement a breast cancer detection program using nurses or community health workers. However, any program screening asymptomatic women should be rigorously evaluated to determine its effectiveness and cost-effectiveness and would require a large sample size and long-term follow-up.

Results from patient interviews also indicated that some women sought help from traditional healers (e.g., spiritualists, herbalists) and tried traditional remedies before being diagnosed and while undergoing treatment, which led to delays in care. Survey findings also suggest some women believe herbal medicine and prayers can be used to treat breast cancer. Traditional healers, therefore, may be important local gatekeepers to engage in the breast cancer help-seeking pathway and encourage them to refer women with suspected breast cancer and those seeking remedies for pain. Future research should

explore the role of traditional healers and the potential to engage them to work with the health system. Additional insight into access to palliative care options and patients' perceptions of palliative care is also needed.

The results of this study suggest future research should also explore preferences for cervical cancer screening in order to tailor the screening program and increase participation. Although Malawi implemented a national program to screen using VIA over a decade ago, participation remains low and many women outside of the recommended screening age range are diagnosed with cancer. Results from qualitative interviews in Chapter 5 described how women expressed modesty and privacy concerns regarding pelvic exams, cervical cancer screening, and the gender of the health worker examining them. Because of the successful administration of the breast cancer DCE, the basic design could also be modified to assess preferences for cervical cancer screening, which is the most common cancer among females in Malawi. However, the relevance of current attributes should be explored through focus groups before testing the design.

There are three additional analyses and manuscripts in development that build on these data. We analyzed the results from the cervical cancer section of the survey (Appendix D) and will move forward to prepare a manuscript for that analysis. For future research, I also plan to use the coded patient transcripts to describe the experiences of patients once they reach the hospital for treatment. The factors leading to delays described in Chapter 4 also contributed to patient's experiences and led to additional consequences for women (e.g., financial problems, family hardships). Finally, we will use the results of the DCE to simulate optimal intervention packages for different groups of women using latent class modeling. This type of analysis will allow us to examine preference differences between groups (e.g., age groups, rural residence) and suggest specific interventions that can be tailored to meet their needs and desires.

Conclusions

This dissertation study has important implications for policy, practice, and future research. The results of these analyses highlight opportunities to increase breast cancer knowledge among the general population and health care providers, improve referrals for suspected cancer, and expand access to early

detection services in settings women find desirable. Overall, the findings provide essential information to maximize strategies for planning and implementing a national breast cancer control program in Malawi, specifically addressing awareness about breast cancer signs/symptoms and potential curability. Together, these findings help build the evidence base toward developing pragmatic and influential cancer control policies and programs for Malawi, in a manner which may also be relevant for similar SSA countries.

By exploring local beliefs, current knowledge, and preferences that influence women's perceptions of breast cancer and early detection behavior, we can design and implement more culturally relevant cancer prevention and early detection interventions. Enhancing breast cancer services and encouraging early detection in SSA have the potential to broadly improve rates of early stage diagnosis and outcomes for women throughout the region.

Breast Cancer Detection and Breast Health Awareness: Provider Interview Guide

<u>Interview Information</u>

        Participant ID: __ __ __ - __ __ __ __

        Site:

        Today's date: __ __ / __ __ __ / __ __ __ __

        Interviewer ID: __ __ __

        Start time:

        End time:

        Recording file:

<u>Introduction</u>

I appreciate you taking time today to talk with me. For this interview, I'll begin with some general questions and then ask you more specific questions regarding preventive care practices in your clinic and breast cancer care services. I would like to record this interview and will also be taking notes.

[Turn on digital recorder]

Do you agree to participate in this digitally-recorded interview?

Thank you. Everything from this interview and our interactions will remain confidential.

<u>General Questions</u>

Tell me about your job. How would you describe your position?

        What department do you work in?

        What are your responsibilities in the clinic? What do you do on a daily basis?

        How long have you been working there?

        What type of educational training do you have? (What are your qualifications?)

How much experience do you have with providing cancer care services? (prevention, detection, or management services?)

- Have you had any type of training in cancer care services? (Is this your specialty?)

<u>Preventive Care</u>

How common is it to have patients come to the clinic for a check-up, when they are not sick? Why do you think that is?

How often do you do a history and physical exam for female patients?

        How do patients typically respond? (Do they seem uncomfortable?) Is this the norm?

What is your experience with cervical cancer screening visual inspection with acetic acid (VIA)?

        How often is VIA provided at the health clinic where you work?

        Do you think most eligible women participate in screening? Why or why not?

How important is cervical cancer prevention and screening?

Breast Health

Now I'm going to ask you some questions about breast health.

Tell me about breast health awareness. What do you think that means?

    How important is it for a woman to be familiar with her breasts?

Do you think it is acceptable to talk about breast health? Why or why not?

    Do you think women feel embarrassed to talk about their breasts? (Why? Is privacy or modesty a big concern?)

    What do you think health care providers could do to help women feel more comfortable?

What do you think about increasing breast health awareness?

    How important is it to promote or encourage breast health?

Breast Cancer Awareness

We would like to hear your thoughts on breast cancer. What do you think about breast cancer?

    Do you think it is a serious disease? Why or why not?

    As a health care provider, do you see breast cancer as an important issue? Why or why not?

    How common do you think breast cancer is? What percent of women do you think develop breast cancer?

Do you think breast cancer awareness needs to be improved?

    Should it be a priority? Why or why not?

    What do you think should be done to improve breast cancer awareness? How can that be accomplished?

Detecting Breast Cancer

We would like to know how you feel about checking for breast cancer.

What do you think about finding breast cancer early?

    What do you think about teaching women to do a breast self-exam?

    How important is it for a woman to know how to detect breast cancer?

    Would you feel comfortable showing a woman how to do it? Why or why not?

Clinical Breast Exam Practices

Have you ever performed a clinical breast exam on a patient to check for problems or lumps who did not have symptoms of a breast problem?

    How often would you say that you perform this type of exam?

    What keeps you from doing this more often?

How important do you think the gender of the medical professional is for things like a breast exam? (Are women more comfortable with other women?)

    What do you think could be done to make female patients feel better about it?

What do you think about performing a clinical breast exam as part of a woman's physical exam or reproductive health visit?

    What about combining breast cancer detection with current cervical cancer screening efforts?

    Who do you think should be responsible for talking to women about breast health?

Treating Breast Cancer

We would like to know what you think about breast cancer treatment.

What do you think about the treatment options patients have for breast cancer?

    What do you think about surgery, chemotherapy?

    Do you think the treatment options are acceptable to women? Why or why not?

What do you think are the most difficult barriers to effective breast cancer management?

    Why do you think woman present with late stage disease?

    What types of things do you think cause delays in breast cancer care? (lack of awareness, cost of care, family roles, fatalism, faith healers?)

What is the most important thing can we do to help improve breast cancer outcomes? Why? How?

Thank you for taking time to be a part of this important study. Is there anything else you would like to share about your thoughts and feelings regarding breast cancer and early detection?

Breast Health Awareness: Breast Cancer Patient Interview Guide

Interview Information
        Participant ID: __ __ __ - __ __ __ __
        Site:
        Today's date: __ __ / __ __ __ / __ __ __ __
        Interviewer ID: __ __ __
        Start time:
        End time:
        Recording file:

Introduction
    I appreciate you taking time today to talk with me. For this interview, I'll begin with some general questions and then ask you more specific questions regarding breast cancer and your health care choices. I would like to record this interview and will also be taking notes.
    [Turn on digital recorder]

    Do you agree to participate in this digitally-recorded interview?

    Thank you. Everything from this interview and our interactions will remain confidential.

    General Questions
    How old are you? (Do you know your birth date?)

    How would you describe your tribal background?

    Do you affiliate with a religious group?
    What is your religion?

    What is your current marital status?
    Do you live with your partner/spouse?

    What is the highest level of education you have completed?
    Did you complete primary school? secondary school?

    Do you have a regular source of income?
    What is your job?
    Does your husband have a regular job? What is his job?

    What area do you live in?
    (If no area in Lilongwe, then what village do you live in?)

    Do you own or rent your home?
    Do you have electricity at your home?
    What type of roof does your home have? (Thatch, Metal, Don't Know)

Health-Seeking Behavior and Preventive Care
Think back to before the breast problem was discovered.
Before that time, did you ever go to the health clinic when you were not sick, for a check-up?

If you get sick, do you usually wait and try to let the problem heal on its own or do you seek medical care right away? Why? How long do you usually wait?
    What types of things kept you from getting help? (cost, distance, responsibilities)

How do you feel about a male health worker helping you? (Do you feel uncomfortable?)
What do you think about going to a faith healer?

Have you ever kept a health problem a secret? Why? (Were you embarrassed? Scared?)
    Were you afraid of what your neighbors might think? Why?
    How do you feel about keeping family health matters private?

Breast Cancer Awareness
Keep thinking about before your breast problem was discovered.
Did you know about breast cancer before the medical professional told you about your breast cancer?
    How did you hear about breast cancer?
        Can you tell me when you first remember learning about it?
    Did you think it was a serious disease? Why or why not?
        What other health conditions were you more worried about?

Detecting Breast Cancer
What do you think about finding breast cancer early before it causes serious symptoms? (Is it possible? Would it be helpful?)

Breast Cancer Knowledge
What do you think causes a woman to develop breast cancer?
Do you believe cancer is contagious? Can it be spread from one person to the next?

Some people think the destiny is important when understanding the causes of cancer. What do you think about God's will and developing cancer?
How do you feel about bad luck and developing cancer?

Breast Cancer Experience
Now think about your breast cancer diagnosis. Who found your breast cancer? (Did you notice something that concerned you? Or did a medical professional find the problem?)

When a woman discovers a problem in her breast, she usually has to think about what to do next before contacting a medical person. What about you?
    How did you first become aware of the problem that was diagnosed as breast cancer?
    What changes in your breast or symptoms did you notice?
    Were you afraid the problem was cancer? Why or why not?

Delay & Barriers
Think about how much time passed after you noticed a problem and before you first told someone else about it.
How long did you wait to talk to someone?
    Was it a few days after finding the problem, or was it more than a week?
    Who did you first tell?
        Did you talk to your spouse, friend, or neighbor? Why did you go to that person?
        How did you feel about talking about a problem with your breast?
        Was there something that made you feel embarrassed?

Sometimes when people have a health problem they wait a while before they get help at a clinic. Think back to the time when you decided to get help with your breast problem.
Did you think the problem would get better on its own?

What types of things made you wait before you decided to get help? (Were you concerned about the cost of medical care? Did you have other things to do at home or at work?)
Did you try other treatments to cure their disease? (What initial steps did you take to remedy the symptoms?)

What kind of effect did your diagnosis have on your family?
    Did you have to stop working?
    How has your family helped support you?

Breast Cancer Treatment
How involved has your family been in your breast cancer care?

Was there anything that kept you from getting treatment? What types of things?
    Were you concerned about the cost?
    Were you afraid of the side effects of treatment?
            What were you afraid of?

What do you think about having a mastectomy, the surgery a medical professional does to remove the breast?
    How did you feel about having the breast removed?
        Were you afraid? Were you worried about losing your breast?
        Were you worried about your relationship with your spouse?

What do you believe about curing breast cancer? (Do you feel like you can be healed? Why?)
When you came to the clinic did you think it was too late to get treated successfully?

What do you think about telling other people that you have breast cancer? Are you afraid?

Thank you for taking time to be a part of this important study. Is there anything else you would like to share about your experience of finding your breast cancer and getting treated?

Breast Health Awareness: Community Participant Interview Guide

Interview Information
        Participant ID: __ __ __ - __ __ __ __
        Site:
        Today's date: __ __ / __ __ __ / __ __ __ __
        Interviewer ID: __ __ __
        Start time:
        End time:
        Recording file:

Introduction
I appreciate you taking time today to talk with me. For this interview, I'll begin with some general questions regarding your health care choices and then ask you more specific questions about breast cancer. I would like to record this interview and will also be taking notes.
[Turn on digital recorder]

Do you agree to participate in this digitally-recorded interview?

Thank you. Everything from this interview and our interactions will remain confidential.

Questions
How old are you? (Do you know your birth date?)

How would you describe your tribal background?

What is your religion?

What is your current marital status?
      Do you live with your partner/spouse?

What is the highest level of education you have completed?
      Did you complete primary school? secondary school?

Do you have a regular source of income?
      What is your job?

What area do you live in?

Do you own or rent your home?
Do you have electricity at your home?
What type of roof does your home have? (Thatch, Metal, Don't Know)

Health-Seeking Behavior and Preventive Care
What do you think about going to the health clinic when you are not sick? (Have you ever done that? Have you ever been to the clinic for a check-up?)

Are you familiar with cervical cancer screening? This is when the medical person uses a special instrument to look at the cervix, which is the opening to the womb.

       Have you ever had a cervical cancer screening test?
              What did you think about getting that test?

If you get sick or have a health problem, do you usually wait and try to let the problem heal on its own?

       How long do you usually wait?
       Do you seek medical care right away?
       What types of things might keep you from getting help? (cost, distance, responsibilities)

How do you feel about discussing personal illness with friends or a family member before seeking help?

       Have you ever kept a health problem a secret? Why?
       Were you embarrassed? Scared?
       Were you afraid of what your neighbors might think? Why?

How do you feel about a male health worker helping you? (uncomfortable?)

What do you think about going to a faith healer?

How do you feel about staying healthy? (Is maintaining good health important?)

Breast Health
How do you feel about talking about your breasts? (Is it uncomfortable? Inappropriate?)
       Do you think women feel embarrassed about other people seeing their breasts?
       What makes it embarrassing?

If you thought you had a problem with your breast, would you tell anyone?
       Who would you talk to? Why?
       Do you know where to go or who to see about a breast problem?

Breast Cancer Awareness
We would like to hear your thoughts on breast cancer.
Did you know about breast cancer before today?
       How did you hear about breast cancer?

What comes to mind when you hear the term *breast cancer*?
       What do you know about breast cancer?
       What does breast cancer do to a woman's body?

Do you know anyone who has been diagnosed with breast cancer?

Do you think it is a serious disease? What are some reasons why?
       Do you think it is dangerous?

Breast Cancer Knowledge
What do you think causes a woman to develop breast cancer?
     Do you believe cancer is contagious? Can it be spread from one person to the next?

How do you feel about bad luck and developing cancer?

Detecting Breast Cancer
We would like to know how you feel about checking for breast cancer.

What do you think about looking for cancer? (Is it bad luck? Is it good for your health?)

What do you know about detecting breast cancer early? What do you think that means?
     Do you think a woman can find breast cancer before it causes serious problems? Why or why not?

How would you feel about getting a test to find out if you have breast cancer?
     Would you want to know if you have cancer? Why or Why not?

Have you ever had a clinical breast exam, when a medical person checks your breasts for problems or lumps?
     What did you think of the clinical breast exam?
     How did you feel having someone examine your breasts? (uncomfortable, embarrassed?)

How would you feel about getting undressed for a medical person to touch and feel your breasts? What about it makes you uncomfortable?

Has anyone ever told you to check your breasts for cancer?
     What do you think about checking your own breasts?

Breast Cancer Treatment
We would like to know what you have heard about breast cancer treatment.
Do you think if a woman has breast cancer, it is already too late for her to get treated for it? Why?

Do you believe a woman with breast cancer can be cured? Why or why not? (What would help make it more likely to be cured?)

Thank you for taking time to be a part of this important study. Is there anything else you would like to share about preventive care or breast cancer detection?

APPENDIX B. QUESTIONNAIRE

A. General

A1.   Participant ID   BCB - __ __ __

A2.   Interviewer Number   __ __ __

A3.   Today's date (e.g., 01/AUG/2013)   __ __ / __ __ __ / __ __ __ __

Today we will be asking you questions about your knowledge of breast cancer and women's health. Some of these questions may be on sensitive topics - please be assured that all of your responses will be kept completely confidential, which means they will not be shared with anyone who is not approved study personnel. There are no "correct" answers to most of our questions. Rather, we want to know about your experiences and your opinions or feelings about these issues. Please try and answer all questions as honestly and fully as possible, but don't worry if you don't know about some of the topics. That's perfectly fine.

If you have any questions at any time throughout the questionnaire, please let me know.

First we'd like to learn a little more about you.

A4.   What is your date of birth? (please fill in as much information as possible)

(e.g., 01/AUG/2013)   __ __ / __ __ __ / __ __ __ __

97	Don't Know

A5.   What is your tribe?

0	Chewa
1	Lomwe
2	Yao
3	Ngoni
4	Lambya
5	Nkonde
6	Other _____

A6.   What is your religion? (Choose one)

0	Christian
1	Muslim
2	No religion
99	Other _____

A7.   What is your current marital status? (Choose one)

0	Never married
1	Married
2	Separated/Divorced
3	Widowed
4	Unmarried & living with a man
98	Refuse to Answer

A8.   How many people live in your house now?   __ __

A9.   What is the highest level of education you have completed? (Choose one)

0	None
1	Primary / Standard 1-7
2	Completed primary school / Standard 8
3	Junior Secondary / Form 1-2
4	Senior Secondary / Form 3-4
5	Completed secondary / General Certificate
6	Any post-secondary / college

A10.   Do you have a regular source of income?

1	Yes
0	No

A11.   What is your job?

0	Farmer
1	Civil Servant
2	Driver/conductor
3	Student/Pupil
4	Unemployed
5	Housewife
6	Business Owner
7	Casual Laborer
99	Other _____

A12.   Where are you based?   __ __

A13.   Do you own or rent your home?

0	Rent
1	Own

A14.   Do you have electricity at your home?

1	Yes
0	No

A15.   Do you have / own a water tap?

1	Yes
0	No

A16.   What type of roof does your home have?

0	Thatch
1	Iron sheet

A17.   Do you own a cell phone?

1	Yes
0	No

B. Health Behaviors

We are now going to ask you a series of questions about your health and health behaviors. Some of these questions are personal – please be assured again that all of your responses will be kept confidential. Please try and answer all questions as honestly as possible. If at any point you have a question, please let me know.

B1.   Has a doctor, nurse, or other health professional ever told you that you have cancer?

1	Yes
0	No

B2.   Have you ever been tested for HIV?

1	Yes, I have been tested
0	No, I have never been tested)
98	Refuse to Answer

If B2 is not equal to 1, then skip to B4.

B2a. What was the result of the HIV test?

1	Positive
0	Negative
98	Refuse to Answer

B3. Are you currently on ARV / antiretroviral therapy?

1	Yes
0	No

B4.   On a scale of 1 to 5, 1 being poor health and 5 being excellent health, how would you rate your physical health?

For example, if you are sick or injured or have a chronic condition, then you might have a lower score. But if you are healthy and physically fit, you might have a higher score.

1	2	3	4	5
Poor	Fair	Good	Very Good	Excellent

B5.   On a scale of 1 to 5, 1 being poor and 5 being excellent, how would you rate your quality of life? (Quality of life is your satisfaction with physical health, mental health, home life, relationships with friends and family, and job)

1	2	3	4	5
Poor	Fair	Good	Very Good	Excellent

B6.	Do you currently smoke cigarettes?	0	Not at all
		1	Some days
		2	Every day
B7.	Do you currently drink alcohol?	0	Not at all
		1	Some days
		2	Every day
B8.	Have you ever been pregnant?	1	Yes, in the past
		0	No, never
		2	Yes, currently

If B9 is equal to 0, then skip to B15.

B9.	How old were you when you got pregnant for the first time?		__ __ years
		97	Don't Know
B10.	How many times have you been pregnant?	__ __	
		98	Refuse to Answer
B11.	How many children have you delivered successfully?	__ __	
		98	Refuse to Answer
B12.	Did you breastfeed your youngest child?	1	Yes
		0	No
		98	Refuse to Answer

If B12 is 0, then skip to B14.

B13.	About how long did you breastfeed your youngest child?		__ __ months
		98	Refuse to Answer
B14.	Have you ever used any contraception or family planning method?	1	Yes
		0	No
		98	Refuse to Answer

If B15 is NOT equal to 1, then skip to B16.

B15.   What type of contraception have you used? (select all that apply)

0	Oral contraceptive pill
1	Injectables
2	Implant
3	Condoms
99	Other _____
98	Refuse to Answer

B16.   Have you stopped having your monthly menstrual cycle/bleeding period?   1   Yes

    0   No

[If a woman is getting injectibles, she might get confused. Be sure she understands it is menopause]

B17.   Have you had a hysterectomy? A hysterectomy is an operation to remove the uterus (womb).

    1   Yes

    0   No

B18.   Have you had a physical exam by a health care professional in the last 6 months?

(Did a doctor examine you in the last 6 months?)

    1   Yes

    0   No

    8   Refuse to Answer

B19.   Where do you usually go when you are sick?

(Bwalia is a district hospital)

    0   Health center

    1   District hospital

    2   Central hospital

    3   Traditional healer

    4   Private hospital

    99   Other _____

B20.   Was there a time in the last 6 months when you needed to see a doctor but could not because of the cost?

    1   Yes

    0   No

    98   Refuse to Answer

C. Cancer Awareness

What follows are some questions related to your current attitude and knowledge with regards to cancer.

C1.   Have you ever known someone who was diagnosed with cancer?   1   Yes

    0   No

    98   Refuse to Answer

    If C1 is NOT equal to 1, then skip to C4.

C2.　　Who was diagnosed with cancer? (check all that apply)

(Aunt, Uncle, Cousin, Grandchild, Grandparent should be marked 3, family member)

0	Main partner/spouse
1	Parent
2	Child
3	Other family member
4	Friend
5	Neighbor
99	Other _____
98	Refuse to Answer

C3.　　Where was the cancer your _____ (insert answer from previous question) was diagnosed with?

Person with cancer	Organ/part of body		
Main partner/spouse	_____	97	Don't Know
Parent	_____	97	Don't Know
Child	_____	97	Don't Know
Other family member	_____	97	Don't Know
Friend	_____	97	Don't Know
Other	_____	97	Don't Know

C4.　　The question I am about to ask you already has some answer choices. I will read them to you so you can choose which ones describe how you feel. ***What do you think about*** doctors checking/screening for cancer?

0	It is better to know to have peace of mind
1	It is a bad idea to look for cancer
2	It is not necessary unless there is a problem
3	It good to get checked to stay healthy
4	I have other problems more important than cancer
99	Other _____

C5.　　***Do you think cancer can be found early BEFORE it causes symptoms?***

1	Yes
0	No
97	Don't know

C6. The question I am about to ask you already has some answer choices. I will read them to you so you can choose which ones describe how you feel. What do you think about finding cancer early? (You may give more than one answer)

0	Treatment might work better
1	It doesn't matter when you find cancer
2	It allows time to prepare for death
3	It reduces chances of dying from cancer
99	Other _____

C7-10. Please tell me if you agree with the following statements:

	Yes	No	Don't Know
C7. A healthy looking person can have cancer	1	0	97
C8. Cancer almost always means severe pain	1	0	97
C9. A diagnosis of cancer is a death sentence	1	0	97
C10. I believe if someone has cancer, it is already too late to do anything about it	1	0	97

C11. Control *of Health*

	Yes	No	Don't Know
C11*a*. Do you think *whatever happens to your health is God's will*?	1	0	97
C11b. Do you think God works through doctors to heal us?	1	0	97
C11c. Do you think prayer is the most important thing to do to stay healthy?	1	0	97

D. Breast Cancer

D1. **Before today, had you heard of breast cancer?**

We want to know if you have ever heard about this disease - breast cancer. Were you aware of it before this interview?

1	Yes
0	No

If D1 is equal to 0, then skip to D10.

D2. **Do you know any signs of breast cancer?**

1	Yes
0	No

D2a-D2j. Please tell me if you think the following things could be signs of breast cancer.

	Yes	No	Don't Know
D2a. Painful breast	1	0	97
D2b. Bloody d*ischarge from nipple*	1	0	97
D2c. Breast lump (hard, thick knot inside breast)	1	0	97
D2d. Sore / boil on the breast (lesion on outside) 1		0	97
D2e. *Discoloration of nipple*	1	0	97
D2f. Nipple turns inward / nipple retraction	1	0	97
D2g. Discoloration of breast	1	0	97
D2h. Change in shape of breast	1	0	97
D2i. Itchy breast	1	0	97
D2j. Skin looks like dried orange peel small dents/holes	1	0	97

D3a-D3n. Please tell me if you think the following may increase the chance of developing breast cancer.

	Yes	No	Don't Know
D3a. Genetic and family history	1	0	97
D3b. Not having children	1	0	97
D3c. *First delivery after 30 years old*	1	0	97
D3d. *Short duration of breast feeding*	1	0	97
D3e. Getting older	1	0	97
D3f. Being overweight	1	0	97
D3g. Fatty diet	*1*	*0*	*97*
D3h. Drinking a*lcohol*	*1*	*0*	*97*
D3i. Smoking	*1*	*0*	*97*
D3j. Clogged milk in breast	*1*	*0*	*97*
D3k. Eating hybrid chickens	*1*	*0*	*97*
D3l. Keeping cell phone in bra	*1*	*0*	*97*
D3m. Keeping money in bra	*1*	*0*	*97*
D3n. Family planning methods	*1*	*0*	*97*

D4.   Do you think breast cancer is contagious?

1	Yes
0	No
97	Don't Know

D5.   Do you think breast cancer is more likely to be treated successfully if it is found early?

1	Yes
0	No
97	Don't Know

D6.   Please tell me whether you agree with the following statements or not:

	Yes	No	Don't Know
D6a. Do you think breast cancer can be cured?	1	0	7
D6b. Do you think breast cancer can be cured by prayer by itself?	1	0	7
D6c. Do you think breast cancer can be cured by going to fellowships?	1	0	7

D7. Please tell me if you think the following options can treat breast cancer:

	Yes	No	Don't Know
D7a. Surgery to remove breast with cancer	1	0	97
D7b. Surgery to remove both breasts	1	0	97
D7c. Pain killers	1	0	97
D7d. Herbal or Traditional Medicine	1	0	97
D7e. Chemotherapy	1	0	97
D7f. Hormonal therapy	1	0	97

D8. Breast Cancer Susceptibility

	Yes	No	Don't Know
D8a.Does the thought of developing breast cancer scare you?	1	0	97
D8b. Do you think you will get breast cancer in the future?	1	0	97
D8c. Are you worried about your chances of developing breast cancer?	1	0	97
D8d. When you think about breast cancer, do you feel nervous?	1	0	97
D8e. When you think about breast cancer, do you get upset?	1	0	97
D8f. If you was diagnosed with breast cancer, would you keep it a secret?	1	0	97

D9. Breast Cancer Barriers	Yes	No	Don't Know
D9a. Do you think breast cancer would hurt a relationship with your boyfriend, husband, or partner?			
	1	0	97
D9b. Do you think being treated for breast cancer would cause you a lot of problems?	1	0	97
D9c. Do you think treatment for breast cancer would be worse than the cancer itself?	1	0	97

D10. ***Have you heard of breast self-examination? This is when a woman checks her breasts for changes and lumps.***

1	Yes
0	No

If D10 is not equal to 1, then skip to D15.

D10a. ***How did you hear about breast self-examination?***

0	Friend/Family
1	Nurse/Doctor
2	community HSA
3	Radio
4	TV
5	Newspaper
6	Health talk at clinic
99	Other_____
97	Don't Know

D10b. ***How often do you think you should check your breasts for cancer?***

0	Daily
1	Weekly
2	Monthly
3	Every Year
97	Don't Know

D11. ***Have you ever done breast self-examination before?***

1	Yes
0	No

If D11 is not equal to 1, then skip to D14.

D11a. How long has it been since the ***last time you performed a breast self-exam?***

__ __ months ago

97   Don't Know

D11b. ***How often do you check your breasts for lumps?***

0	Daily
1	Weekly
2	Monthly
3	Every Year
97	Don't Know

D12. BSE Self Efficacy	Yes	No
D12a. Do you know how to perform a breast-self exam?	1	0
D12b. Are you confident that you can perform breast-self exam correctly?	1	0
D12c. Do you regularly check your breasts for lumps?	1	0

D13. BSE Benefits	Yes	No
D13a. When you perform breast-self exam, do you feel good about yourself?	1	0
D13b. Do you perform breast-self exams to have peace of mind?	1	0
D13c. Do you perform breast self-exams because a doctor told you to?	1	0
D13d. Do you think if you find a lump through a self-exam, treatment may not be as bad?	1	0

D14. *Do you think performing regular breast self-exams would help you find breast cancer when it is just getting started?*

1	Yes
0	No

[All women should be asked this question:]

D15. *If a health worker taught you how to perform a breast self-exam would you start to do them?*

1	Yes
0	No

D16. BSE Barriers	Yes	No
D16a. Are you afraid to do a self-exam because you might find out something is wrong?	1	0
D16b. Do you think doing a breast self-exam would take too much time?	1	0
D16c. Do you think you could do a breast self-exam correctly?	1	0
D16d. Do you have other problems more important than doing a breast self-exam?	1	0

D17. *Have you heard of a clinical breast exam? This is when a medical professional looks at and feels a woman's breasts for changes and lumps.*

1	Yes
0	No

If D17a is not equal to 1, skip to D21.

D17a. *How did you hear about clinical breast exams?*

0	Friend/Family
1	Nurse/Doctor
2	HSA
3	Radio
4	TV
5	Newspaper
6	Health talk
99	Other_____
97	Don't Know

D18. *Has a health care professional ever examined your breasts FOR CANCER?*

1	Yes
0	No
8	Refuse to Answer

If D18 is not equal to 1, skip to D21.

D19a. *When was the last time you had a clinical breast exam?*

__ __ months ago

97	Don't Know
98	Refuse to Answer

D19b. *Have you ever had an abnormal clinical breast exam? (Has a doctor ever found a lump?)*

1	Yes
0	No
98	Refuse to Answer

D19c. *Where did you have the clinical breast exam?*

0	Health center
1	District hospital
2	Central hospital
3	Private hospital
99	Other _____
97	Don't Know

D19d. *Who checked your breasts?*

0	Doctor
1	Nurse
99	Other _____

D19e. *What was the gender of the person who checked your breasts?*

0	Male
1	Female
97	Don't know

D19f. *What was your experience of the clinical breast exam? (select all that apply)*

0	Painful
1	Painless
2	Embarrassing
3	Uncomfortable
5	Other _____
98	Refuse to Answer

D19g. *Would you have a clinical breast exam done again?*

1	Yes
0	No
97	Don't know
98	Refuse to Answer

D20. CBE Benefits

	Yes	No
D20a. When you get a clinical breast exam, do you feel good about yourself?	1	0
D20b. When you got a breast exam, did you worry less about breast cancer?	1	0
D20c. Did you get a clinical breast exam to have peace of mind?	1	0
D20d. Did you get a clinical breast exam because a health care provider told you to?	1	0

D21. *If a health worker offered to do a clinical breast exam, would you be willing to do the exam?*

1	Yes
0	No

[Only women who answered NO/0 to D18]

D22. CBE Barriers

	Yes	No
D22a. Are you afraid to have a CBE because you might find out something is wrong?	1	0
D22b. Do you know where to get a CBE?	1	0
D22c. Would you be embarrassed about my body if you had a CBE?	1	0
D22d. Do you think having a CBE would take too much time?	1	0
D22e. Do you think having a CBE would be too painful?	1	0
D22f. Would your husband/partner approve of you having a breast exam?	1	0

[All women]

	Yes	No
D23a. Do you have other problems more important than getting a CBE?	1	0
D23b. Do you think you are too young to need a CBE?	1	0
D23c. Do you think a breast exam is not needed because you do not have any symptoms?	1	0
D23d. Do you think it would be difficult to get transportation to have a clinical breast exam?	1	0

D24. CBE Benefits

	Yes	No	Don't Know
D24a. Do you think having a CBE will help find lumps early?	1	0	97
D24b. Do you think having a CBE will decrease your chance of dying from breast cancer?	1	0	97
D24c. Do you think having a CBE will help find a lump before you can feel it?	1	0	97

D25. Health-seeking attitudes

	Yes	No
D25a. Do you want to discover health problems early?	1	0
D25b. Is maintaining good health extremely important to you?	1	0
D25c. Do you think it is important to take action to improve your health?	1	0
D25d. Do you rush to the doctor when you get sick?	1	0

D26. Would you like to know more about breast cancer and how to detect breast cancer?

1	Yes
0	No

D27.   How would you like to get information about breast cancer detection?

0	Doctor
1	Community health worker
2	HSA
3	Radio
4	Reading material
5	Ladies seminars at church/school
6	Health talk
7	TV
8	Other_____

E. Cervical Cancer

E1.   Have you ever heard of cancer of the cervix?

1	Yes
0	No

E2.   Have you ever heard of human papillomavirus or HPV? (HPV is different from HIV. HPV is a sexually transmitted virus).

1	Yes
0	No

If E1 is NOT equal to 1, skip to E9.

E3.   Please tell me if you think the following things can cause cervical cancer.

	Yes	No	Don't Know
E3a. HIV	1	0	97
E3b. HPV	1	0	97
E3c. The Devil	1	0	97
E3d. The Plague	1	0	97
E3e. Family planning methods	1	0	97
E3f. Sexually transmitted infections (STIs)	1	0	97
E3g. Washing genitals with soap	1	0	97
E3h. Being unfaithful to your partner	1	0	97

E4.   Do you think you are at risk of developing cervical cancer?

1	Yes
0	No
97	Don't know

E5.   Does the thought of getting cervical cancer scare you?

1	Yes
0	No

E6. Please tell me if you think the following things can increase your risk of getting cervical cancer.

	Yes	No	Don't Know
E6a. Early sexual activity	1	0	7
E6b. Multiple sexual partners	1	0	7
E6c Human papillomavirus (HPV)	1	0	7

E6d. HIV	1	0	7
E6e. Poor personal hygiene	1	0	7
E6f. Exposure to STIs	1	0	7
E6g. Smoking	1	0	7

E7. Please tell me if you think the following options can PREVENT cervical cancer.

	Yes	No	Don't Know
E7a. Use condoms	1	0	7
E7b. The HPV vaccine	1	0	7
E7c. Limit the number of sexual partners	1	0	7
E7d. Don't smoke	1	0	7
E7e. Have cervical cancer screening	1	0	7

E8. Please tell me if you think the following health tests can detect cervical cancer:

	Yes	No	Don't Know
E8a. Visual inspection with acetic acid (VIA)	1	0	7
E8b. Pap smear test	1	0	7
E8c. HIV testing (VCT)	1	0	7
E8d. Biopsy (surgical tissue sample)	1	0	7

Every respondent should be asked this question:

*E*9. ***Have you ever heard of VIA screening?*** (VIA is when a health care provider put vinegar on your cervix to look for abnormalities like cervical cancer)

1	Yes
0	No

If E9 is NOT equal to 1, skip to E13.

E9a. ***How did you hear about VIA?***

0	Friend/Family
1	Nurse/Doctor
2	HSA
3	Radio
4	TV
5	Newspaper
6	Health talk
99	Other_____
97	Don't Know

E10.   Have you had VIA screening?

1	Yes
0	No

If E10 is equal to 0, skip to E13.

E11a.   When did you last have a VIA screening test?

__ __	months ago
97	Don't Know

E11b.   Where did you have the VIA screening?

0	Health center
1	District hospital
2	Central hospital
3	Private hospital
99	Other _____

E11c.   Who performed the cervical cancer screening test?

0	Doctor
1	Nurse
99	Other _____
97	Don't know

E11d.   What was the gender of the person who did the cervical cancer screening test?

0	Male
1	Female
7	Don't know

E11e.   The question I am about to ask you already has some answer choices. I will read them to you so you can choose which ones describe how you feel.

What was your experience of the cervical cancer test? (select all that apply)

0	Painful
1	Painless
2	Embarrassing
3	Uncomfortable
99	Other____
98	Refuse to Answer

E11f.   Have you ever had an abnormal result (or positive VIA)?

1	Yes
0	No
98	Refuse

E11g.   Would you have it done again?

1	Yes
0	No

E12. VIA Benefits

	Yes	No
E12a When you got screened for cervical cancer, did you feel good about yourself?	1	0
E12b. When you had VIA screening, did you worry less about cervical cancer?	1	0
E12c. Did you have the VIA screening to have peace of mind?	1	0
E12d. Did you have the VIA screening because a health care provider told you to?	1	0
E12e. Did you have the VIA screening because of bleeding?	1	0
E12f. Did you have the VIA screening to know about your body's health?	1	0

[Go to E15]

E13. *If a health professional offered to do VIA cervical cancer screening, would you be willing to do the test?*

1	Yes
0	No

E14. VIA Barriers	Yes	No
E14a. Are you afraid to have VIA because you might find out something is wrong?	1	0
E14b. Are you afraid to have VIA because you do not understand what will be done?	1	0
E14c. Do you know where to go to have VIA screening?	1	0
E14d. Would you be embarrassed about your body if you had VIA?	1	0
E14e. Do you think having VIA would take too much time?	1	0
E14f. Do you think having VIA would be too painful?	1	0
E14g. Would your husband does not approve of you having VIA screening?	1	0

[Every respondent should be asked these questions]

	Yes	No
E15a. Do you have other problems more important than getting VIA screening	1	0
E15b. Do you think you are too old to need a VIA?	1	0
E15c. Do you think you do not need VIA because you do not have any symptoms?	1	0
E15d. Did you know you need to go for VIA screening?	1	0

	Yes	No	Don't Know
E16. Do you think having VIA screening will help the doctor find cancer early?	1	0	97
E17. Do you think having VIA screening decreases your chances of dying from cervical cancer?	1	0	97

E18.   Would you like to know more about cervical cancer and how to prevent it?

1	Yes
0	No

E19.   How would you like to get information about cervical cancer screening?

0	Health care professional
1	Community health worker
2	HSA
3	Radio
4	Reading material
5	Ladies seminars at church/school
6	TV
7	Other_____

Preference Assessment Tool

We would like to provide more breast health services for women. We would like to know what is important to you when you decide to get medical care.

We think you'll find this next section both interesting and perhaps a bit challenging. We are going to display a number of tradeoff scenarios. These are some descriptions of things you might consider when you make a decision to get medical care.

Transportation

When you go to a health facility, you might have to travel a distance and walk by foot. Some facilities are closer to your house and are a shorter walk. Other facilities may be further away and take longer to get there on foot. Travel time in this exercise is described as less than 1 hour by foot, 1-2 hours by foot, and more than 2 hours by foot.

Health workers

Different people help us with medical concerns. You may have a doctor assist you or you may talk to a HSA. You may also prefer to talk to a man or a woman.

Type of health visit

Sometimes, when you are at a health facility, a health worker may offer you additional services after they treat your main concern. We want to know your preferences for where you would like to be offered breast cancer services. The options include a community health meeting, health talk at a hospital, during a cervical cancer screening visit, during a family planning visit, and during an under 5 child health visit.

Breast cancer early detection

There are a few ways to help detect breast cancer early. You can learn about breast health awareness and how to do a breast self-exam, where you learn how to check your breasts for symptoms. You can also have a clinical breast exam where a health worker will look at and feel your breasts for any signs of breast cancer. The final option is that you would learn about breast health and also have a clinical breast exam.

Directions

In this section I will show you 9 cards. Each card describes one possible health care visit. Imagine that you are deciding to participate in a breast cancer early detection visit. Please tell me which health care setting you prefer. We are only interested in learning about what is important to you about health centers. There are no right or wrong answers to these questions.

Let's try a practice question first.

Practice. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel more than 2 hours by foot	You travel 1-2 hours by foot
2:15	1:30
You meet with a doctor. The health worker assisting you is a woman	You meet with a HSA. The health worker assisting you is a man
Your child has a health check	You go for cervical cancer screening (VIA)
You can have a clinical breast exam (CBE)	You can learn about breast health awareness
You walked more than 2 hours to a hospital for your child's health check. While you are there a female doctor offers to do a clinical breast exam on you.	You walked 1-2 hours to have cervical cancer screening at a hospital. During your appointment a male HAS offers to teach you about breast health awareness.

Which would you choose?

Do you understand what you have to do?

Remember, you have to choose one setting, even though you might prefer some things from each one. Okay, now it is your turn.

1. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel 1-2 hours by foot	You travel more than 2 hours by foot
You attend a health talk at a hospital	Your child has a health check
You meet with a HSA	You meet with a HSA
The health worker assisting you is a woman	The health worker assisting you is a man
You can learn about breast health and have a clinical breast exam (CBE)	You can learn about breast health awareness

Which would you choose?

2. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel less than 1 hour by foot	You travel more than 2 hours by foot
0:45	2:15
You attend a community health meeting	You go for a family planning visit
You meet with a doctor	You meet with a doctor
The health worker assisting you is a woman	The health worker assisting you is a man
You can learn about breast health and have a clinical breast exam (CBE)	You can learn about breast health awareness

Which would you choose?

3. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care..

Setting A	Setting B
You travel 1-2 hours by foot	You travel less than 1 hour by foot
You attend a health talk at a hospital	Your child has a health check
You meet with a doctor	You meet with a HSA
The health worker assisting you is a man	The health worker assisting you is a woman
You can learn about breast health and have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose?

4. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel 1-2 hours by foot	You travel less than 1 hour by foot
You go for cervical cancer screening (VIA)	You go for a family planning visit
You meet with a HSA	You meet with a doctor
The health worker assisting you is a woman	The health worker assisting you is a man
You can learn about breast health and have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose?

5. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel more than 2 hours by foot	You travel less than 1 hour by foot
You go for cervical cancer screening (VIA)	You go for cervical cancer screening (VIA)
You meet with a doctor	You meet with a doctor
The health worker assisting you is a woman	The health worker assisting you is a woman
You can have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose?

6. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel less than 1 hour by foot	You travel more than 2 hours by foot
You attend a community health meeting	You attend a health talk at a hospital
You meet with a doctor	You meet with a HSA
The health worker assisting you is a man	The health worker assisting you is a man
You can learn about breast health and have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose?

7. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel more than 2 hours by foot	You travel 1-2 hours by foot
You go for a family planning visit	You go for cervical cancer screening (VIA)
You meet with a doctor	You meet with a HSA
The health worker assisting you is a woman	The health worker assisting you is a woman
You can learn about breast health and have a clinical breast exam (CBE)	You can learn about breast health awareness

Which would you choose?

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8. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel 1-2 hours by foot	You travel less than 1 hour by foot
Your child has a health check	You go for a family planning visit
You meet with a doctor	You meet with a HSA
The health worker assisting you is a man	The health worker assisting you is a woman
You can have a clinical breast exam (CBE)	You can have a clinical breast exam (CBE)

Which would you choose?

9. Imagine you are at a health visit and you are offered early breast cancer detection services. Choose one of these two settings where you could get breast health care.

Setting A	Setting B
You travel more than 2 hours by foot	You travel 1-2 hours by foot
You go for a family planning visit	Your child has a health check
You meet with a doctor	You meet with a HSA
The health worker assisting you is a woman	The health worker assisting you is a man
You can learn about breast health awareness	You can learn about breast health and have a clinical breast exam (CBE)

Which would you choose?

This is the end of the questionnaire. Is there anything else that you'd like to share with me today about your thoughts regarding breast cancer, cervical cancer, or cancer generally?

Thank you for your time and help on this important study.

Breast Cancer Facts

What is breast cancer?

Cancer is a disease when cells in the body grow out of control. When cancer starts in the breast, it is called breast cancer. Sometimes cells in the breast grow faster than normal cells. These extra cells form a mass called a tumor. Some tumors are cancerous and have the ability to spread to other parts of the breast and body.

All women are at risk for breast cancer. It is the second most common cancer in Africa.

Some things may increase your risk

A risk factor is anything that changes your chance of getting cancer. Several factors may affect your risk of developing breast cancer, including:

- Getting older
- Not having children, or having your first child later in life
- Starting your first menstrual period at an early age
- Beginning menopause at a late age
- Having close family relatives (such as a mother, sister, or daughter) who have had breast cancer
- Being overweight, particularly after menopause
- Drinking alcohol
- Being physically inactive

What are the symptoms?

When breast cancer starts, it is too small to feel and does not cause signs and symptoms. As it grows, breast cancer can cause changes in how the breast looks or feels. Some warning signs of breast cancer may include:

- A lump or thickening in the breast
- A change in the size or shape of the breast
- Pain in the breast or nipple that does not go away
- Flaky, red, or swollen skin anywhere on the breast
- A nipple that is very tender or that turns inward
- Blood or any other type of fluid coming from the nipple that is not milk when nursing a baby

These symptoms may be caused by something other than cancer, but the only way to know is to get checked. *If you have any signs that worry you, see your doctor right away.*

How can I find out if I have breast cancer?

Women should talk to their doctor about when and how often they should be checked for breast cancer. If you have any risk factors or symptoms of breast cancer, talk to a health care professional.

A clinical breast exam is when a doctor or nurse will ask you to undress from the waist up. The clinician will look at your breasts for abnormalities and will gently feel your breasts and underarms. *An abnormal breast exam does not always mean you have cancer.* It does mean that you will need to have some additional x-rays or other tests before your doctor can be sure. You may be referred to an oncologist or a surgeon because these doctors are experts in diagnosing breast problems.

Treatment is most effective when breast cancer is found early, and many women go on to live healthy lives.

Cervical Cancer Facts

What is cervical cancer?

Cancer is always named for the part of the body where it starts, even if it spreads to other body parts later. When cancer starts in the cervix, it is called cervical cancer. The cervix is found at the end of the vagina (birth canal) and is the part of the uterus (womb) that opens when a baby is born.

Cervical cancer is the most common cancer in Malawi. *But it is can be prevented with regular screening tests and a new vaccine.* It also is highly curable when found and treated early.

What puts me at greater risk?

The main cause of cervical cancer is human papillomavirus (HPV), which is a common virus that can be passed from one person to another during sex. Many people will have an HPV infection at some time in their lives, but because HPV usually goes away on its own, few will get cervical cancer.

Several other factors may affect your risk of developing cervical cancer, including:

- Smoking
- Having HIV or another condition that makes it hard for your body to fight off viruses
- Becoming sexually active at an early age
- Having multiple sexual partners
- Having given birth to three or more children

What are the symptoms?

Early on, cervical cancer may not cause signs and symptoms. Advanced cervical cancer may cause bleeding or discharge from the vagina that is not normal for you, such as bleeding after sex. *If you have any of these signs, see a health care provider.* The symptoms may be caused by something else, but the only way to know is to get checked.

How can I find out if I have cervical cancer?

Visual inspection using acetic acid (VIA) is the main screening method in Malawi. During VIA, a health care provider will ask you to undress from the waist down. The provider will then put a speculum in your vagina and put vinegar on your cervix. If there are any abnormal areas on your cervix, the vinegar will cause these areas to look different than the rest of your cervix.

If the VIA test is positive, do not panic. Your health care provider can often treat abnormal areas on the cervix and can refer you to have extra tests to be sure that it is abnormal. Women with abnormalities may be recommended to have the abnormal area frozen or removed. Women with cancer may be referred for surgery to remove the uterus. The earlier an abnormal area is found, the more likely it can be treated and cured.

How can I prevent cervical cancer?

There are many ways to prevent or reduce your risk for cervical cancer:

- If you are HIV-positive, you should have a VIA done every year. If you are on ART, make sure that you take your medicines.
- If you are HIV-negative, you should have VIA every 5 years.
- Don't smoke.
- Use condoms during sex with new partners.
- Limit your number of sexual partners.
- Talk to your health care provider about getting the HPV vaccine.

APPENDIX D. CERVICAL CANCER ANALYSIS

Of the 213 women in the sample, 120 (56%) were aware of cervical cancer. Most women learned about cervical cancer from a health worker (46, 38%), family member or friend (30, 25%), the radio (26, 22%), or a health talk (14, 12%).

Women who were aware of cervical cancer were more likely to be married, have higher education levels, live in urban areas, have access to a water tap and electricity in their homes, and have an iron sheet roof (Table 1). Those who had been tested for HIV, had a physical exam in the past six months, and who knew someone diagnosed with cancer were also more likely to be aware of cervical cancer.

In multivariable logistic regression, women with no formal schooling had significantly lower odds of being aware of cervical cancer (AOR 0.39, 95% CI: 0.16 - 0.95). Women who had been tested for HIV and those who knew someone with cancer had significantly higher odds of being aware of cervical cancer (AOR 4.12 95% CI: 1.59-10.66 and AOR 6.65, 95% CI: 3.04-14.5, respectively).

Of those who were aware, most (77, 64%) did not know how cervical cancer was detected. One-third (40) said VIA, however only 9 women had heard of cervical biopsies or pap smears. Most women did not know that HPV infection leads to cervical cancer (87%); however, a majority of women believed HIV, STIs, being unfaithful, and having poor hygiene caused cervical cancer (Table 2). Over half of the sample thought washing with soap could cause cervical cancer. Most (94%) knew at least one risk factor; the mean score across seven risk factors was 4.3. HPV, HIV, and smoking were risk factors the fewest women identified. The mean score of five prevention measures was 3.59. Over 90% of the sample knew that having a limited number of sexual partners and cancer screening were ways to prevent cervical cancer; however, most women did not know about the HPV vaccine and over 20% thought condoms were not a preventive approach. Summing the correct cause, risk factors, and prevention responses, the mean cervical cancer knowledge score was 8.07 out of 12. In multivariate linear regression, having electricity at home was associated with significantly higher knowledge scores compared to not having electricity.

Only 14 women from the full sample had ever heard of HPV; however, 44 women (21%) were aware of VIA. Health workers were the most commonly mentioned source of information for VIA (23, 52%); women also learned about screening from family or friends (9, 20%) the radio (7, 16%), or a health talk (7, 16%).

Among the women with knowledge of VIA, 27 (61%) had been screened and 17 of them had the exam within the past 2 years. Half (14) of those screened had the procedure at the central hospital, 6 went to the district hospital, and 6 went to a health center or private clinic; one woman reported that she was screened at church. Most recalled a doctor doing the exam (19, 70%), and half (14) said they were assisted by a female health worker. Five women said they went for VIA because of persistent bleeding. Fifteen women thought the exam was painless; however 4 said it was a painful exam and 9 thought VIA was embarrassing. All of the women who had VIA experience and had not undergone a hysterectomy said they would do it again (27).

Of the women who knew about VIA but had never been screened (17), most knew where VIA was available; only six women did not know where to get screened. Five women thought it might be painful, and two worried that their husband/partner would not approve of the exam; however, only one thought it might be embarrassing. All but two of the women said they would accept a health worker's invitation to VIA; the two refusals said they were scared or uninterested in the exam.

Ten of the women who had never heard of VIA were not interested in getting screened. Most women preferred to learn more about cervical cancer screening from a doctor (125, 59%), a community health worker (84, 40%), the radio (40, 19%), a health talk (34, 16%), or a health surveillance assistant (17, 8%). A few women were interested in information from written materials, television, and bridal showers.

Table 1. Bivariate analysis of sample characteristics

	Not aware of cervical cancer N = 93 (44%)	Aware of cervical cancer N = 120 (56%)	Total N = 213	p-value
Age (*mean, standard deviation*)	39.2 (16.5)	37.3 (12.6)	38.1 (14.4)	0.17
Religion				0.18
Christian	74 (79.6)	101 (84.2)	175 (82.2)	
Muslim	8 (8.6)	13 (10.8)	21 (9.9)	
No religion	11 (11.8)	6 (5.0)	17 (8.0)	
Married	72 (77.4)	105 (87.5)	177 (83.1)	0.05
Education level				0.002
No formal school	28 (30.1)	14 (11.7)	42 (19.7)	
Primary	39 (41.9)	55 (45.8)	94 (44.1)	
Secondary	26 (27.6)	51 (42.5)	77 (36.1)	
Rural	53 (57.0)	42 (35.0)	95 (44.6)	0.001
Economic characteristics				
Electricity	18 (19.3)	42 (35.0)	60 (28.2)	0.01
Water tap access	24 (25.8)	56 (46.7)	80 (37.6)	0.002
Iron sheet roof	63 (67.7)	105 (87.5)	168 (78.9)	<0.001
Health service indicators				
Physical exam within past 6 months	22 (23.7)	46 (38.3)	68 (31.9)	0.02
Tested for HIV	63 (67.7)	109 (90.8)	172 (80.8)	<0.001
Ever used contraception	67 (72.0)	99 (82.5)	166 (77.9)	0.07
Cancer awareness outcomes				
Aware of HPV	1 (1.1)	13 (10.8)	14 (6.6)	0.004
Aware of VIA	1 (1.1)	43 (35.8)	44 (20.7)	<0.001
Peer cancer-related experience	13 (14.0)	54 (45.0)	67 (31.5)	<0.001

Notes: HIV, human immunodeficiency virus; HPV, human papillomavirus; VIA, visual inspection with acetic acid

Table 2. Cervical cancer knowledge among Malawian women* (n=120)

	Yes (n)	%	No (n)	%	Don't know (n)	%
Causes						
HPV	16	13.3	5	4.2	99	82.5
HIV	78	65.0	20	16.7	22	18.3
Sexually transmitted infections	105	87.5	9	7.5	6	5.0
The devil	58	48.3	56	46.7	6	5.0
The plague	58	48.3	52	43.3	10	8.3
Family planning methods	61	50.8	39	32.5	20	16.7
Washing genitals with soap	66	55.0	37	30.8	17	14.2
Being unfaithful to partner	98	81.7	12	10.0	10	8.3
Poor hygiene	77	64.2	35	29.2	8	6.7
Risk factors						
Sexual activity at young age (early debut)	107	89.2	6	5.0	7	5.8
Multiple sexual partners	109	90.8	4	3.3	7	5.8
HPV	26	21.7	5	4.2	89	74.2
HIV	92	76.7	17	14.2	11	9.2
Sexually transmitted infections	105	87.5	8	6.7	7	5.8
Smoking	83	69.2	25	20.8	12	10.0
Mean score[†] (sd)	4.35	(1.55)				
Prevention						
Condoms	80	66.7	27	22.5	13	10.8
HPV vaccine	40	33.3	2	1.7	78	65.0
Limited number of sexual partners	112	93.3	4	3.3	4	3.3
Not smoking	89	74.2	22	18.3	9	7.5
Cervical cancer screening	110	91.7	4	3.3	6	5.0
Mean score[†] (sd)	3.59	(1.22)				

Notes: *includes 120 women aware of cervical cancer
† Number of women who responded yes
sd, standard deviation

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