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Assessing the Percieved Barriers to Early Detection, Treatment, and Management of Cervical Cancer among Ghanaian Women

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ASSESSING THE PERCEIVED BARRIERS TO EARLY DETECTION, TREATMENT, AND MANAGEMENT OF CERVICAL CANCER AMONG GHANAIAN WOMEN

by

ANGELA DENISE BLACKWELL

(Under the Direction of Samuel Opoku)

ABSTRACT

Introduction: The purpose of this study was to assess the perceived barriers and strategies for improvement of timely detection, treatment, and management of cervical cancer among Ghanaian women in a tertiary hospital setting. **Methods:** Sixty semi-structured interviews, comprised of thirty-five cervical cancer patients and twenty-five healthcare professionals who provide cervical cancer care, were conducted. Two focus groups were conducted, including four healthcare professionals and another with two healthcare professionals—the data were analyzed using NVivo 12. A theoretical thematic analysis was utilized to identify common themes and sub-themes that arose from the participant interviews. The social-ecological model framework was employed to classify themes. **Results:** Lack of knowledge about the disease, screening, perceived lack of susceptibility and seriousness, cost of diagnostic test, treatment, travel, and accommodations coupled with a low socio-economic status are barriers at the *individual level*. Lack of financial and social support from family and normative gender relations were the barriers at the *interpersonal level.* The sociocultural beliefs in the communities associated with the causes of the disease, stigmatization, and alternative healing were barriers at the *community level.* There are several barriers at the *organizational level* that effect timely detection, treatment, and management. These barriers are associated with the availability and access to adequate health systems and trained health professional such as lack of diagnostic facilities, high levels of misdiagnosis, delay in release of results, inefficient referral process, poor patient-provider communication, difficult patient navigation, lack of treatment equipment, maintenance and resources, lack of psychosocial support, and lack of palliative care services. Lack of government-sponsored education programs, funding allocated for health facilities and trained healthcare professionals in the rural settings and tertiary health facilities, drug stockpile, inadequate insurance coverage, and timely reimbursement of insurance claims for hospitals pose significant barriers at the *policy level*. Strategies proposed for improvement were centered around education, community outreach and sensitization, health system improvements, and increased community organization and government support. **Discussion:** Cervical cancer early detection, treatment, and management outcomes face several barriers at the various level of the SEM. To improve detection time, treatment, and management issues, these barriers at all levels must be addressed simultaneously.

INDEX WORDS: Social-ecological model, Barriers, Cervical cancer, Early detection, Diagnosis, Treatment, Management, Patient perspective, Provider perspective, Ghana

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by

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DOCTOR OF PUBLIC HEALTH

ASSESSING THE PERCEIVED BARRIERS TO EARLY DETECTION, TREATMENT, AND MANAGEMENT OF CERVICAL CANCER AMONG GHANAIAN WOMEN

by

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DEDICATION

I would like to dedicate this dissertation to my close family and friends who rode with me from the beginning to the end. The journey was not comfortable caring for a family, working full-time, and attending graduate school all at the same time. By the grace of God and a lot of support, encouragement, kind words, harsh real-talk words and plenty of shoulders to lean and cry on along the way, I made it. Thank you to ALL my support system. You know who you are near and far. This one is for you. WE made it.

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CHAPTER 1

INTRODUCTION

Background

Cancer, also called malignant tumors and neoplasms, is defined by the National Cancer Institute (NCI) as the abnormal division of cells without control that can invade and spread to other parts of the body (2019). Several types of cancer fall into four major categories (carcinoma, leukemia, lymphoma, and central nervous system. (National Cancer Institute, 2019). Gynecologic cancers are the type of carcinoma that develops in women, specifically their reproductive organs. According to the American Cancer Society, there were an estimated 110,070 new cases diagnosed and approximately 32,120 deaths from gynecologic cancers in the U.S. in 2018. The five main types of gynecologic cancers that affect a woman's reproductive organs are cervical, ovarian, uterine, vaginal, and vulvar. According to the World Health Organization (WHO), cervical cancer is the fourth most frequent cancer in women, with an estimated 570,000 new cases in 2018 representing 6.6% of all female cancers and 311,000 deaths worldwide (Bray et al., 2018).

Cancer profile differences occur across individual countries and between regions suggesting that geographic diversity remains prevalent, with local risk factors in low middle-income countries (LMICs) that are at various phases of social and economic development. Geographic diversity is seen in Africa by infection-driven cancers such as cervical cancer versus what is observed in more developed countries. (Bray et al. 2018). The western world incidence and mortality rates of cervical cancer are seven to ten times lower than those of LMICs, such as sub-Saharan Africa and Eastern Asia. Approximately 90% of deaths from cervical cancer from 2015-2019 occurred in LMICs in Asia, Africa, Latin America, and the Caribbean (Vaccarella et al., 2017; WHO, 2019). Africa has the highest regional incidence and mortality rates associated with cervical cancer (Bray et al., 2018).

There were an estimated 99,000 new cases and 60,000 deaths documented in Africa in 2012, and incidence rates were highest in West African countries (Ghana, Senegal, Liberia, and Mali) (Ferlay et al., 2013). According to the Joint United Nations Program on HIV and AIDS (UNAIDS), cervical cancer is also the most common cancer among women living with HIV worldwide. The rate of invasive cervical cancer is five times higher among women infected with HIV. The overall risk of HIV acquisition among women doubled among those with the human papillomavirus (HPV) infection. Cervical cancer is similar to HIV in that the disease is fueled by social, economic, and political inequities. Lower-income countries bear the highest-burden, with nearly 80% of all cervical cancers and 90% of deaths. Cancer diagnostic factors affect treatment outcomes and have a direct impact on mortality and survival rates. Therefore, detection and timely diagnosis can improve overall treatment options, management planning, and overall quality of life for women with cervical cancer. Cervical cancer is entirely preventable with the aid of the HPV vaccine currently available on the market. Cervical cancer is also curable at low cost and low risk when detected early via screening, coupled with the appropriate diagnosis, treatment, and follow-up (Lewis, 2004). A concerning prognostic factor for cervical cancer that directly affects outcomes is the stage of cancer at diagnosis. Women who undergo annual pelvic examinations and Pap smears have a higher chance of any abnormalities or pre-cancerous tissue being detected during the early stages, which can play a crucial role in successfully preventing or treating cervical cancer. Up to 95% of cervical cancer patients in African countries are diagnosed in late-stage or end-stage disease.

Researchers began collecting data regarding cervical cancer in 1975. Since 1975, the U.S. has experienced an increase in the number of newly diagnosed cases and mortality rates among women with cervical cancer, despite the decline in the incidence and mortality rate of cancer overall in the U.S. (CDC, 2018). Efforts to address cervical cancer in the U.S. have been very successful due to increased prevention measures. However, racial disparities exist among minorities in cervical cancer awareness, such as (causes, signs, and symptoms), prevention efforts, time to diagnosis, and access to adequate treatment and management options, especially among women of color. According to the CDC, Black women in the U.S. account for 8.6 per 100,000 (approximately 1, 953 new cases of a population of more than 23 million) women who are newly diagnosed; that number is higher with 9.4 per 100,000 (approximately 2,221 new cases of a population of over 27 million) Hispanic women (National Cancer Institute, 2019). Black women were more likely to die from cervical cancer than any other group of women. Hispanic women had the second-highest death rate from cervical cancer, followed by American Indian/Alaska Natives, White, and Asian/Pacific Island women (National Cancer Institute, 2019). In the developed world, cervical cancer is slowly declining, despite the racial disparities. Still, the opposite is being seen in Sub-Saharan Africa and other less developed parts of the World, and the disparities have a much wider margin. The continuing global demographic and epidemiologic evolutions signal an ever-increasing cervical cancer burden over the next decade in LMICs. According to WHO current disparities in survival from cervical cancer, vary from 33-77% and if the medical community does not scale up efforts now to prevent, detect, and respond to cervical cancer issues in low resource countries, death rates will increase by 50% as early as 2040 (WHO, 2019).

Rates of cervical cancer are often underestimated in developing countries like sub-Saharan Africa because of significant challenges due to sparse data capturing methodologies (Bray et al., 2018). Cancer data is more readily available in real-time with improved accuracy through improved hospital documentation beginning with the population-based Kumasi Cancer Registry in 2004, which suggests a higher incidence of cancer than previously reported estimates in the literature (Ohene-Yeboah et al., 2012). Smaller cancer registries like the population-based Kumasi Cancer-Registry are essential because they are considered unbiased estimates of cancer in a well-defined population, which are essential when developing evidence-based cancer prevention and control programs specific to Ghana. (Bray et al., 2018). They also can provide accurate real-time data for national cancer estimates that inform resource allocation in LMICs such as Ghana.

Purpose Statement

In Ghana, cervical cancer is the 2nd most prevalent cancer but has the highest mortality rate of cancer in Ghana (International Agency for Research on Cancer. (2018). Approximately 8.57 million women over the age of 15 are currently at risk of developing cervical cancer. Each year in Ghana, approximately 3,100 women are diagnosed with cervical cancer, and at least 2,100 women, more than 65%, die from cervical cancer (International Agency for Research on Cancer, 2018). Ghanaian women's cumulative risk is three times the global cumulative risk. Population-based Kumasi Cancer Registry from 2004-2012 documents that cervical cancer represents 20-25% of all cancers among women in Ghana (Opoku, 2018). In the absence of a screening program in Ghana, most women with invasive cervical cancer are diagnosed in an advanced stage. At the oncology directorate at Komfo Anokye Teaching Hospital (KATH), almost 80% of the women with cervical cancer present with the disease at advanced stages (stages III and IV), which leads to poor outcomes. Treatment and management options are often limited to palliative care. The social and ecological factors potentially associated with an advanced stage of cervical cancer at diagnosis and the barriers to providing effective treatment and management are not well defined in this population.

Cervical cancer mainly occurs in women who are either uninsured or underinsured. Women of certain racial, ethnic minorities, lower educational levels, and poverty levels do not use Papanicolaou (Pap) tests (Parkin et al., 2003). As stated previously, cervical cancer screening using the Pap test detects not only cancer but also precancerous lesions. Detection and treatment of precancerous lesions found during a Pap test can prevent cervical cancer, as well as diagnose cervical cancer at an early stage when it is most curable. Women should begin getting a Pap test with the onset of sexual activity, but no later than 18 years of age. Girls and boys who have not encountered their first sexual experience should receive the HPV vaccination. There has been a significant increase in the number of studies reporting the assessment of the diagnosis of cervical cancer in recent times as compared to twenty years ago (Zarama et al., 2003). Due to Pap testing, detection, and treatment of cervical pre-cancerous lesions, a decline in incidence in the US and deaths in the past 40 years has been seen (CDC, 2017).

Despite the advances in prevention (HPV vaccination and routine screening), treatment options, and management planning in the developed world, there is no systematic nationwide program or policy for HPV vaccination, cervical cancer screening, standardized treatment, or management options implemented in many of the LMICs. This lack of national policy likely played a significant role in the advanced stage at presentation of cervical cancer and significantly higher mortality rates seen in these regions. The average person, absent of screening, will not present initially to the doctor unless they are in pain, which could lead to delayed diagnosis and treatment. Non-governmental organizations have been working to help break down obstacles that tend to make people present at a late stage for some time (Holly et al., 1992). A stable government-funded cervical cancer early detection program can assist in screening low-income, uninsured, and underserved women, and this can help save them from presenting in the late stage of the disease, which leads to death from the cancers (Holly et al., 1992). Despite many advances in knowledge in the developed world, trends continue to point to high incidence and mortality rates of cervical cancer in LMICs such as Ghana.

Previous studies in Ghana and other LMICs have assessed sociodemographic factors that influence the late-stage presentation of cervical cancer in terms of age, educational background, financial, social status, and parity (Nartay et al., 2018). Very few studies have assessed factors such as the insurance, hospital setting/access, level of preventive care, quality of care, religious and cultural beliefs, and other community, organizational, and societal-related factors. The purpose of the study is to fill gaps in the scientific literature by identifying the perceived social and ecological barriers to timely detection, treatment, and management of cervical cancer from the patient and provider perspective. Most public health issues in LMICs are complex and often multi-faceted. To develop cost-effective, culturally sensitive prevention and control programs that can be successfully implemented, requires a better understanding of perceived barriers at the various levels of influence beyond essential sociodemographic characteristics of the individual. This will better inform decision-makers and other relevant stakeholders what practical cervical cancer prevention and control programs are needed. Then evidenced-based policies and mandates geared towards early detection and timely diagnosis can be developed and implemented. This will allow patients access and equip healthcare providers with the necessary tools and resources to provide appropriate treatment and management options for cervical cancer patients in Ghana and other LMICs.

Social-ecological Model Framework

The Social-Ecological Model (SEM) is a theory-based framework for understanding, exploring, and addressing the social determinants of health at many levels. The SEM encourages us to move beyond a focus on individual behavior and toward an understanding of the full range of factors that influence health outcomes. The social-ecological approach is the use of the SEM in research to determine the social factors. “Ecological” means multiple levels beyond the individual that impact the health of your target population (Institute of Medicine, 2003). Thus, the SEM hypothesizes that behavior is the result of the knowledge, attitudes, and beliefs of individuals as well as social influences, including the people with whom they associate, the organizations they are affiliated with, and the communities in which they live.

The primary goal of cervical cancer research in public health is prevention through routine screening and HPV vaccination in sexually naive males and females. The secondary goal is improving timely diagnosis, treatment outcomes, and overall quality of life of those affected by cervical cancer. Early detection and diagnosis require understanding the factors that influence health-seeking behaviors. The SEM has been used as a health promotion model by CDC to develop national cancer programs (CDC, 2019). This model considers the complex interplay between individual, interpersonal, community, organization, and societal factors and, therefore, was chosen as the theoretical framework to conduct this study. The SEM will allow for a better understanding of the range of factors that put women at risk for cervical cancer and factors that influence appropriate health-seeking behaviors that can prevent cervical cancer or detect it early. The overlapping rings in the SEM will illustrate how factors at one level influence factors at another level. Besides helping to clarify these factors, the SEM model also hypothesizes to prevent cervical cancer, detect it early, properly treat or manage it when it occurs, it is necessary to act across the multiple levels of the model at the same time. This approach is more likely to sustain prevention and control efforts over time and improve treatment and management at a higher level than individual targeted interventions impact. Often public health interventions, especially in LMICs, fail because the many complex factors that play a part are not addressed. Additional information for the SEM and its relevancy to this research will be discussed in detail in chapter two.

Main Objective

Given the exploratory and qualitative nature of the current study, no hypotheses are being tested. Instead, this study seeks to generate information that can be used to develop hypotheses about Ghanaian women with cervical cancer and their perceived barriers to timely detection, treatment, and management as well as how the barriers can be understood from the patient and healthcare providers' perspective within a social-ecological framework. Therefore, the main objective of this study is to utilize a social-ecological approach to critically examine the perceived barriers to early detection, treatment, and management of cervical cancer and to identify the multiple complex levels of interaction influencing these barriers at the individual, interpersonal, community, organizational and societal level.

Specific Aims

1. Determine the perceived social and ecological barriers and facilitators to early detection, treatment, and management of cervical cancer from the patient’s perspective.
2. Determine the perceived social and ecological barriers and facilitators to early detection, treatment, and management of cervical cancer from the health professional’s perspective.

Research Questions

Based on the problem statement, the research, therefore, seeks to answer the following questions:

1. What are cervical cancer patient's perspectives on barriers to timely health-seeking behavior, treatment, and management of cervical cancer in Ghana?
2. What are cervical cancer patients' perspectives on strategies to improve cervical cancer care in Ghana?
3. What are healthcare professionals' perspectives on barriers to early detection, diagnosis, treatment, and management of cervical cancer in Ghana?
4. What are health professionals' perspectives on strategies to improve cervical cancer care in Ghana?

Delimitations

Hospital records were reviewed to confirm cervical cancer diagnosis, stage at presentation, and other sociodemographic characteristics. When the diagnosis or stage at presentation could not be determined, or the patient's diagnosis according to the patient's record was not cervical cancer, the patients were excluded. Referral patients seen at KATH from neighboring countries were not eligible to participate due to potential social, economic, and cultural biases based on residential regional differences

Assumptions

- All participants responded truthfully to the best of their knowledge and understanding of the discussion.
- The interview guide questions and probes adequately addressed the participants perceived barriers and facilitators to early detection, treatment, and management of cervical cancer across all levels of the SEM.

Significance of the Study

Cancer trends from 2004 to 2012 point to a high incidence of cervical cancer in Ghana, with most women presenting with stage III and IV cancer (Laryea et al., 2014). Previous studies have looked at some of the demographic factors that are predictors of delayed detection and diagnosis of cervical cancer at the individual level such as age, educational background, financial or social status, but not much is known about factors that are perceived barriers to early detection and diagnosis, or influence on treatment and management at the community, organizational and societal level. Additionally, no previous research has tried to access patient fully, and health systems mediated factors (adequate staffing, specialized healthcare personal, the referral pathways, patient navigation, screening practices, etc.) in limited-resource environments. Determining factors that predict delayed detection and diagnosis can influence policy and resource allocation. Government-sponsored targeted education about the importance of prevention through vaccination, routine screening can be developed. Understanding of these factors can improve overall treatment and management options for cervical cancer in Ghana. This study was designed with the intent to fill the gaps in this area of cancer research, extend knowledge for future research, and inform policy and resource allocation decisions in LMICs such as Ghana and other parts of sub-Saharan Africa. Palliative care is often the only treatment option when the late-stage presentation of cervical cancer occurs, significantly decreasing the survival rate and quality of life among these women and their families. Therefore, understanding the complex interaction of the individual, interpersonal, community, organizational, and societal level can potentially provide evidenced-based strategies to ultimately improve cervical cancer prevention, control, and overall quality of life for women in Ghana and other similar LMIC settings.

CHAPTER 2

LITERATURE REVIEW

This literature review provides an overview of the social-ecological model (SEM) framework. A comprehensive summary of the existing barriers to cervical cancer timely detection, treatment, and management in Ghana and other low-and middle-income countries (LMICs), noted in the literature, are discussed. Additionally, other studies that utilized the SEM for cervical cancer research are provided with a brief description of their strengths and weaknesses compared to the current study.

Introduction

Cervical cancer continues to be a prominent global health issue around the world, with some of the hardest-hit areas in the African regions. Researchers have gained a better understanding of the causes and risk factors for cervical cancer and have proceeded to implement better prevention, treatment, management, and control measures. Research conducted across the world over-time has shown multiple factors contributing to the high prevalence and incidence rates of cervical cancer. As stated, the rates of cervical cancer seen in LMICs tend to be significantly higher than that of more developed countries such as the U.S., Canada, and Europe.

Researchers began collecting data regarding cervical cancer as early as 1975. There has been a consistent rise in newly diagnosed cases and deaths due to cervical cancer, despite the overall decline in cancer rates in the U.S. (Centers for Disease Control and Prevention, 2018). Efforts to address cervical cancer in the U.S. continue to make great strides due to increased cost-effective prevention and control measures. Unfortunately, the same trends in prevention, early detection, timely diagnosis, and treatment are not being seen in LMICs. The prognosis and outcomes of late-stage cancer presentation in LMICs remains disproportionate. Furthermore, racial disparities exist in cervical cancer awareness, routine screening by way of Papanicolaou (Pap) tests among women of color even in the more developed countries like the U.S. According to the CDC, Black women in the U.S. account for 8.6 per 100,000 (approximately 1,953 incidence cases of a population of more than 23 million). Rates are even higher for Hispanic women 9.4 per 100,000, approximately 2,221 newly diagnosed cases of a population of over 27 million (NCI, 2019).

In the U.S., a quality cancer registry data has been available for about four decades. In LMIC's, the cancer registry data is very sparse, and there is a growing need for an adequate account of cancer prevalence and incidence to ensure cost-effective prevention and control measures are implemented in these countries. In 2012, the Kumasi Cancer Registry was launched, making it the first population-based cancer registry in Ghana. The registry was developed to accurately track pertinent information on cancer cases seen in the city of Kumasi at a tertiary hospital that sees most of the advanced stage cervical cancer patients in Ghana (Laryea et al., 2014). In 2014, females accounted for 69.6% of cancer cases, with cervical cancer 29.4%, ovarian cancer 11.3%, and endometrium cancer 4.5% (Laryea et al., 2014. A similar study was conducted in Kumasi on malignant tumors in urban Ghana, and it was revealed that, overall, cervical cancer was the second most prevalent cancer recorded. In 2015, breast cancer accounted for 19.7% of all cancer cases in Kumasi, followed by cervical accounting for 14.7%. Among females, the most prevalent cancer recorded was breast cancer (accounting for 30.0% of all cases), followed by cervical (23.4%) (Amoako et al. 2019). Since data collection began, there has been an increase in documentation of women presenting with advanced-stage cervical cancer. Researchers have suggested that late-stage presentation in Ghana is due to a lack of knowledge and awareness of cervical cancer causes, symptoms, and perceived susceptibility.

According to the World Health Organization (WHO) (2018), the high rates of chronic comorbidities and infectious diseases such as HPV and HIV are also contributing factors. When combining this with a lack of access to adequate health care services, routine screening, and vaccination in the African region, there are significantly higher rates of preventable disease (World Health Organization, 2018). Human Immunodeficiency Virus (HIV) is an infectious disease that is a known risk factor for increased chances of developing cervical cancer. Ghana is disproportionately affected by HIV rates, which can potentially contribute to high incidence and mortality rates of cervical cancer as well (World Health Organization, 2019). Studies have shown that many LMICs settings have a high prevalence of non-HPV 16/18 types that may be associated with high rates of HIV infections (Robadi, Pharaon, & Ducatman, 2018).

Geographic patterns of infection and the overall risk associated with each subtype of HPV must be taken into consideration when determining screening and vaccination priorities. Visual inspection with acetic acid (VIA) is a screening method used to detect aceto-white lesions on the cervix. One minute after 3% – 5% freshly prepared acetic acid is added, the lesions can be detected. VIA is recommended in LMICs due to low-cost feasibility as a single-visit approach (SVA) for screening (Sankaranarayanan et al., 2014). Diagnosis can be made rapidly, and treatment provided the same day, which may eliminate the need for additional follow-up visits, which tend to have meager compliance rates in LMICs. This can allow for timelier and cost-efficient screening and treatment of precancerous cells in LMICs like Ghana that have limited resources and many patients who are lost to follow-up (Msyamboza et al., 2016; Parham et al., 2015; Shiferaw et al., 2016). The World Health Organization (2018) has issued guidelines for implementing SVA screening in LMICs in sub-Saharan Africa. The screening strategy chosen must be culturally sensitive, acceptable, accurate, and easily accessible to women with the highest risk in Ghana. A combination of HPV vaccination and appropriate screening measures has enormous potential to eliminate cervical cancer in Ghana. Therefore, understanding the many factors that influence health-seeking behavior for women in Ghana that lead to late-stage detection and diagnosis of cervical cancer can potentially be translated into the development of feasible and sustainable early detection, treatment, and management programs.

Social-ecological Model Framework

The social-ecological model (SEM) framework developed by McLeroy et al. (1988) was applied to conceptualize how improvement in timely detection, treatment, and management of cervical cancer could be achieved by understanding the reciprocal interrelationships between individual and population-level determinants of behavior. The SEM approach was designed to identify the challenges or perceived barriers at each level that potentially influenced time to diagnosis and treatment outcomes of cervical cancer and examined how they interrelate to influence positive behavior change (See Table 1; McLeroy, Bibeau, Steckler, & Glanz, 1988). Examining each level and considering them can lead to appropriate, cost-effective, culturally competent strategies to prevention and control of cervical cancer among women in Ghana and other LMICs.

Table 2.1: Social-Ecological Model Framework

Level of Influence	Definition of Level
Individual	Individual characteristics that influence behavior: knowledge, attitudes, and beliefs
Interpersonal	Interpersonal processes and groups providing identity and support
Community	Cultural and community norms and association with community organizations
Organizational	Institutions systems, rules, regulation, policies, structures constraining or promote behaviors
Societal	Regulations and policies or laws that regulate or support healthy practices/action

Many factors at the individual level such as knowledge of cervical cancer, attitudes, and beliefs toward screening, causes of cervical cancer, susceptibility, need for prevention and treatment of cervical cancer directly influence a women's health-seeking behavior patterns. Women are also affected by their social network, which includes friends, families, work, school environments, cultural norms, and stigmas that dictate or influence the health-seeking behaviors of individual women. According to the SEM, when exploring beyond the individual, interpersonal, and community level, the organizational and policy influences also must be considered. Perceived barriers at each of these levels, such as inadequate health care facilities, lack of adequately trained healthcare personal, lack of accessible healthcare services, mandated cost-efficient screening for sexually active women, and timely referral to proper diagnosis and treatment of cervical cancer must be considered. According to Finocchario-Kessler et al., there has been a significant increase in research findings within a policy, biomedical, and behavioral levels, thus pointing out some advancements in cervical cancer-related prevention, treatment, and management in the western world that have not transferred to less developed countries (2016).

Even with the advancement in information and data regarding cervical cancer, there is still a gap in providing culturally competent and applicable cervical cancer education to those in LMICs such as Ghana (Williams, 2014). As a result, significant gaps in knowledge occur around cervical cancer awareness among women, men, their families, and the communities at large. The inconsistencies in cervical cancer information disseminated or shared among Ghanaian populations through social and cultural networks negatively influence the attitudes and beliefs towards causes, symptoms, susceptibility, and risk factors for cervical cancer. It also skews their perception of the need and effectiveness of prevention through HPV vaccination, routine screening, early detection, timely diagnosis, and treatment. Healthcare professionals may lack the knowledge of appropriate cervical cancer prevention and control, which could lead to a delay in referral, missed diagnosis, and poor outcomes due to the late-stage presentation as well.

The SEM conceptualizes health broadly and focuses on multiple factors that can affect health. This broad approach to thinking of health, advanced in the 1947 Constitution of the World Health Organization, and it includes physical, mental, and social well-being of the individual (World Health Organization, 1947). The Ministries of Health, according to WHO, was one of the first organizations established to address the concerns surrounding cervical cancer. The WHO was charged with the task of implementing priority cancer control that cuts across the continuum of care covering prevention, early detection, diagnosis, treatment, and palliative care services. The SEM framework conceptualizes the perceived barriers to health and health-seeking behaviors to be affected by the interaction between the different levels (Israel et al., 2003; Sallis et al., 2008; Wallerstein et al., 2003). Therefore, the model is deemed appropriate to identify factors that contribute to poor outcomes of cervical cancer among women in Ghana and can be translated into prevention, treatment, and management options through targeted interventions that eliminate barriers at all levels and facilitate positive health-seeking behaviors. This approach focuses on the need to understand the influence of behavior change associated with the physical and social environment rather than focusing only on individual health behaviors. Individualistic interventions that do not factor in social influence do not lead to long-term prevention and control Israel et al., 2003.

There are positive attitudes and beliefs among organizations such as the Ministries of Health that evidenced-based cervical cancer prevention efforts are scalable to promote cervical cancer awareness in LMICs. Still, the community, health workers engagement, is also needed. There needs to be a shared responsibility approach in educating individuals and communities in Ghana and other LMICs about cervical cancer using individuals closest to the community and understand the cultural landscape. Therefore, community health worker engagement was pertinent to ensure perceived barriers of the community itself were understood and addressed appropriately at each level to educate individuals successfully and ultimately implement sustainable routine screening, mandated healthcare coverage for screening, and HPV vaccination of young girls and boys before their first sexual experience. Efforts to educate policymakers and organizations about necessary resources to ensure individuals, stakeholders must embrace availability and uptake of culturally sensitive prevention, treatment, and management options, and the community at large to improve cervical cancer outcomes among women in Ghana.

In the U.S. and other developed countries, health promotion has increasingly embraced community engagement, defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” (Centers for Disease Control and Prevention, 1997, p. 9). In general, the goals of community engagement are to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as research evolve into sustainable prevention and control programs (Center for Disease Control and Prevention, 1997; Shore, 2006; Wallerstein, 2002). This concept can be applied in LMICs such as Ghana by first exploring the perceived barriers at all levels and using the outcomes to tailor specific intervention and prevention measures to the Ghanaian community needs. The rationale for assessing the Ghanaian cervical cancer patients, health care professionals, community health workers and other key-informants in their natural setting is because social norms, behaviors, and the incidence of delayed detection and diagnosis of cervical cancer are all influenced by social and physical environments that make up the community in which they live (Hanson, 1988; Institute of Medicine, 1988). Understanding the influence at each level beyond the individual social and behavioral determinants of health are required to develop sustainable prevention, treatment, and management plans to ultimately decrease incidence and mortality due to cervical cancer among women in Ghana.

Individual Level Barriers

Socioeconomic and demographic characteristic. Resources to foster early detection and diagnosis in Ghana are limited. One study by Dunyo, Effah, and Udofia (2018) examined the sociodemographic and clinical characteristics associated with the late detection and diagnosis of cervical cancer in women seen in a district hospital in Ghana. Researchers studied 157 medical records and evaluated them for factors such as education, employment status, marital status, place of residence, access to the hospital, and insurance membership number (Dunyo et al., 2018). Notably, patients diagnosed with late-stage cancer had no education, which comprised three-quarters of the total cases reviewed (Dunyo et al., 2018). A quantitative approach using Pearson's chi-square test was utilized, and approximately 66% of the individuals in the study presented with late diagnosis of cervical cancer. Those who had not been screened for cervical cancer were four times more likely to receive delayed diagnosis compared to those who received screening.

With the late-stage presentation of cervical cancer, primary healthcare factors affect the outcome of women being diagnosed, especially in tertiary hospitals. Mwaka et al. (2016) described the factors that lead to the late detection of cervical cancer for women at a tertiary hospital in Northern Uganda. In this study, Mwaka et al. use a hospital-based cross-sectional design to examine the incident rates of late presentation "to inform policies to improve survival from cervical cancer in LMICs (Mwaka, 2016). A correlation was seen between individual-level barriers such as education level, age, and marital status. Financial ability to pay for diagnostic testing also posed as a barrier to women seeking healthcare promptly (Mwaka et al., 2016; Mwaka et al., 2013).

With a country like Ghana, whose gross domestic product (GDP) per capita was last recorded at approximately 2,045 US Dollars compared to the United States GDP per capita of over 20 million US dollars in 2017, access to resources such as medical care already makes it a challenge to seek healthcare promptly ("Ghana GDP," 2019). The socioeconomic status of women in Ghana poses major barriers to timely detection, treatment, and management of cervical cancer.

Knowledge, Attitudes, and Beliefs

According to the Centers for Disease Control and Prevention (CDC) (2019), approximately 80% of people will get an HPV infection at least once in their lifetime. HPV is classified as a sexually transmitted disease and can be transmitted from skin-to-skin contact. Although it is recommended for women to begin cervical cancer screening at the age of 21 to prevent cervical cancer, HPV vaccines should be administered at age 11 or 12 (Centers for Disease Control and Prevention, 2019). While these statistics provide information for women within the United States, research shows that this information would be acceptable to provide for those in Ghana as well, not only to advocate for the implementation of the HPV vaccine but also to encourage the implementation of the vaccine earlier than the recommended age due to the early age of marriage, first sexual encounter and acceptability of polygamy in the African culture which can increase the risk of HPV infection. One study provided by Berenson and Croissant (2017) indicated that this was necessary due to adolescent girls in Africa, indicating that they engaged in sexual behavior before the age recommended by the CDC Thirty-three percent of the girls stated that they had sexual intercourse before the age of 13 years (Berenson & Croissant, 2017). Furthermore, adolescent girls who engage in sexual behavior before they reach the age of 13 years old are more likely to have sex without the use of contraception such as a condom, and more likely to have several sexual partners (Lara & Abdo, 2016). This increases the risk of contracting HPV that can lead to cervical cancer.

In Nigeria, a study conducted by Okunowo et al. (2018) among 205 women in a tertiary hospital showed the majority, 78.5%, of women, were aware of cervical cancer. Still, the risk of susceptibility was shallow 16.6% (34) that only 22.4% of women were aware of HPV and 83.9% (172) were not aware that a vaccine for HPV existed. In another study conducted in Ghana by

Binka et al. (2017), all the women interviewed (n = 15) did not know about cervical cancer before diagnosis and expressed surprise at the situation in which they found themselves. Although education is necessary for implementation at the interpersonal level, further measures need to occur at the organizational level to include more comprehensive methods to provide prevention.

Interpersonal Level Barriers

Social and Familial Influences

According to Williams, beliefs are influenced by social-cultural norms that affect a person's health, especially when deciding to get screened for cervical cancer (Williams et al. 2014). Regarding education, what tends to work in one country does not necessarily work in another country. For instance, providing printed information in the United States, may not be the most accurate and useful method of educating women in Africa, especially in countries in which literacy levels are low.

Additionally, social and cultural norms play a factor in education regarding timely detection and cervical cancer. Gender roles also influence women from getting screened and presenting to the hospital for diagnosis and treatment. For instance, Johnson stated, "Sex-role belief systems, or perceptions of how men and women should behave in society, are learned and culturally determined" (Johnson et al., 2017, p. 203). Gender roles affect early detection due to a lack of knowledge that men are susceptible to HPV, thus being able to pass it on to women during sexual intercourse, despite a woman being with one partner (Williams & Amoateng, 2012). Also, in Ghana, men are the primary decision-makers for when a woman presents to the hospital for treatment. The financial responsibility falls on the men, so they must understand they understand the need for timely detection, treatment, and management of cervical cancer. A study conducted by Binka et al. 2019 assessed the critical role men play in reducing cervical cancer burden. Information on male involvement in cervical cancer screening and treatment process in Ghana was assessed. In-depth interviews and focus group discussions were conducted among a total of 41 respondents, including cervical cancer patients, their male partners, and other married men in a rural District in Ghana. A thematic analysis was conducted. Findings showed that male partners have little or no knowledge about cervical cancer. Some men provide various forms of support–financial, social, material, and emotional–to their partners during the screening and treatment stages of the disease. Some men, however, abandoned their partners during the screening and treatment process of the disease (Binka et al. 2019).

Additionally, the family structure plays a role in health outcomes, which also affects cervical cancer screenings. In the United States, it is encouraged for women between the age of 21 to 29 to get Pap screenings every three years and to obtain HPV testing every five years, along with the Pap screening, between the age of 30 to 65 (Center for Disease Control and Prevention, 2019; U.S. Preventive Services Task Force, 2018). The frequency of Pap smears increases as risk factors increase. Within Africa, since the mother and grandmother primarily influence the children, community-level education and information dissemination is necessary to influence the acceptability of cervical cancer screenings. In one study, Francis et al. (2011) discussed knowledge and beliefs about HPV, in addition to women communicating with female children regarding HPV, HPV vaccines, Pap tests, and transmission. The study was consistent with other studies in that it revealed a lack of knowledge regarding HPV, the vaccine, and Pap tests. The study also revealed the influence that women have over their children’s health, and that because of the respect factor, grandmothers influence the decision of mothers regarding their children’s health and well-being. Therefore, educating the women in the family is necessary for advocating for preventive measures and appropriate health-seeking behavior for diagnosis and treatment. Women in Uganda also indicated that communication regarding symptoms was discussed with family or husbands, which also attributed to the late presentation of cervical cancer due to a lack of urgency in seeking medical attention.

Community Level Barriers

Religious Beliefs

Among the cultural and social norms that play a part in the prevention and late-stage presentation of cervical cancer, religious beliefs play a part in the attitudes towards Pap tests, HPV infection, vaccines, treatment, and management (Drain et al., 2002). A study conducted in the North Central region of Nigeria utilized a focus group comprised of 49 people who identified with a religion: 27 identified as Christians, and 22 identified as Muslims (Modibbo et al., 2016). The results showed that many Muslim women had misconceptions about cervical cancer, and that it was “witchcraft” or a result of multiple sex partners. In contrast, Christian women knew what cervical cancer screening was, and that it could be used to prevent cervical cancer. Historically, women in predominantly Muslim countries or who identify as Muslims had the lowest incident rates of cervical cancer, while women who identify as Christian or are from Christian countries had the highest (Drain et al., 2002). Mutambara et al. (2017) used a cross-sectional study design to examine the knowledge, attitudes, and practices regarding cervical cancer screening among women in Zimbabwe who were members of a Traditional Church. Results showed that many women indicated that going to a hospital for treatment is considered unholy, thus preventing them from seeking attention until they felt concerned or saw signs of cervical cancer lesions (Mutambara et al., 2017).

Cultural Beliefs, Stigmatization, and Misconceptions

Women in LMIC countries are being diagnosed with cervical cancer in advanced stages of the disease. According to Williams-Brennan et al. (2012), in 2008, the age-standardized incidence rate was as follows: 30 for every 100,000 per year in Eastern and Western Africa, 26.8 for every 100,000 per year in Southern Africa, and 23 for every 100,000 per year in Middle Africa. In the same areas of Africa, the stigma surrounding cervical cancer screening presents as a perceived barrier to early-stage presentation. Williams-Brennan et al. (2012) discussed how women in China and Taiwan were less likely to go into medical facilities to be screened for cervical cancer due to the stigma attached to cervical cancer screening for unwed mothers. Williams-Brennan et al. performed an extensive systematic literature review regarding the social determinants of cervical cancer. They determined that women felt guilt and shame, and various negative stigmas were associated with cervical cancer screening. For instance, cervical cancer screening may imply promiscuity among women, given that it is a sexually transmitted disease. Promiscuity is frowned upon in the African culture. Furthermore, misconceptions surrounding pain associated with the Pap test often lead individuals to shun away from screening even if they were knowledgeable and saw a benefit to screening (Williams-Brennan et al., 2012).

The HPV vaccination is one of the most effective methods in preventing cervical cancer caused by the high prevalence of HPV 16/18 infection in sexually naive males and females that cause the majority of the HPV associated cervical cancer cases (Finocchario-Kessler et al., 2016). However, most women within Sub-Saharan Africa will not seek medical attention for gynecological issues unless pain is present (Mutambara et al., 2017; Stewart et al., 2018). Additionally, women in this population admitted to not having cervical cancer screening, despite having a positive attitude regarding receiving a Pap test. Researchers documented the women's perceived barriers as lack of knowledge, religious beliefs that prevented access to medical care, and a belief that cancer was untreatable (Mutambara et al., 2017).

There are many misconceptions regarding the HPV vaccine, especially among countries where access to education and promotion of the vaccine is limited. While access to the HPV vaccine is a contributing factor, knowledge, and beliefs surrounding the vaccine itself also present a barrier to prevention and early-stage presentation of cervical cancer. In a study by Degarege et al. (2018), researchers analyzed the inequalities between urban and rural areas and parental attitudes and beliefs regarding the HPV vaccine, HPV infection, and cervical cancer in Mysore, India. The researchers sought to determine if there were differences in attitudes and beliefs among the two populations that ultimately affected the outcome of HPV infection, vaccination, and cervical cancer. There were 1,609 parents in both urban and rural areas who participated in the study. Approximately 73.6% of parents had never heard of HPV, while 63.7% of parents did not believe that the HPV vaccine was effective (Degarege et al., 2018). In Africa, these numbers are much higher.

Ramathuba and Ngambi (2018) studied the attitudes and beliefs of women toward the HPV infection itself as well as the vaccine in rural Limpopo Province, South Africa. A quantitative approach was used to obtain data for women 30 years of age and older and found that almost all (97.8%) of the women indicated that they did not know about the HPV vaccine, and were not “aware of the transmission methods of HPV virus” (Ramathuba & Ngambi, 2018, p. 111). Approximately 92.1% of individuals exhibited negative attitudes toward receiving the HPV vaccine, with 94.3% not being aware of how to obtain the vaccine, who is eligible, and the age recommendation for obtaining the vaccine. This information is not surprising since HPV is equated to that of HIV and brings about a stigma associated with both the disease and the vaccination (Finocchario-Kessler et al., 2016; Mutambara et al., 2017; Ramathuba & Ngambi, 2018). Furthermore, many women who are sexually active and are at increased risk do not perceive that they are susceptible if they are sexually active with one man (i.e., married). This belief presents a barrier to early diagnosis of cervical cancer, and as well as further education of women on the importance of the HPV vaccine and pap tests.

Organizational Level Barriers

Access to Preventive Health Services

Cervical cancer is the second leading cause of cancer and the leading cause of cancer deaths among women in the Sub-Saharan African region (Black & Richmond, 2018). Prevention measures in Sub-Saharan Africa need to include the implementation of cervical cancer screening via Pap tests (Johnson et al., 2018). However, implementing Pap tests as a prevention method is difficult due to the lack of infrastructure necessary to perform cytology tests in a laboratory. LMICs have limited resources; therefore, maintaining laboratories is often may not be feasible from an economic standpoint (Johnson et al., 2018). The Pap test, which is a resource-intensive method, is available in hospitals and clinics in urban cities in Ghana (Blumenthal et al., 2007). VIA does not require laboratory processing; therefore, it can be used in rural, resource-poor areas in Ghana, especially as VIA was adopted as part of Ghana’s National Cervical Prevention Program (Sanghvi et al., 2008).

A study was conducted by Awua et al., 2018 to determine strategies for cervical cancer screening uptake. The initial recruitment was for individuals to come to hospital facilities, and the response rate was meager. The strategies for recruitment was revised to conduct the specimen collection within the communities. Only 60 (38.5%) of 156 participants who opted to report after a week at the hospital, reported. Of the 118 participants who opted to report within one week at the hospital, 55 (46.6%) reported. Of the 103 participants who were invited to report at a specified location within the community, 98 (95.1%) reported. Community-based strategies are needed for cervical cancer screening to improve uptake (Awua et al., 2018).

Access to Standard Health Care Facilities, Equipment, and Resources

Drislane et al. stated that medical illnesses in Ghana overlap with those in developed countries, but infection, trauma, and women's health problems are much more prominent. Medical practice in rural Africa faces extremely limited resources, a multiplicity of languages (hundreds in Ghana), and presentation of severe illnesses at later stages than seen elsewhere (2014). Perhaps compared to other West African countries, Ghana has the best national insurance system. However, high-quality medical care, access to medical facilities and care remain a considerable challenge, in addition to medical facilities being short-staffed, and medical costs becoming too costly to maintain, even for prevention measures (Drislane et al., 2014). Ghana's health systems in Kumasi and Accra are more developed than the smaller towns. Therefore, the lack of access to healthcare in smaller towns increases the cases of cervical cancer in Ghana.

Human resource development, implementing systems of care, and procuring supplies needed to provide the current resource-intense standard of care for cervical cancer may take years even in more advanced settings where resources may be available. There had been a continued challenge to access, and poor access can lead to delays in treatment and less than standard outputs (Wu et al., 2017). A study in New Delhi reported a median of 41 days from registration to radiation therapy initiation; 25% of patients did not complete therapy (Kaur et al., 2013)

In an option to treat early-stage cervical cancer in lower-resource settings, Wu et al. described how cervical cancer spreads by local extension to the endocervix, uterine corpus, parametrium, and vagina. It could also spread through lymphatic channels to the pelvic lymph nodes, which confers a worse prognosis. A classical study was done with patients with stage I cervical cancer disease who were treated with radical hysterectomy, tumor size, depth of invasion, and lymphovascular space invasion was independent prognostic factors of survival. There was an 85.6% 3-year disease-free survival rate (DFS) with negative nodes and 74.4% 3-year DFS with positive nodes (Wu et al., 2017). DFS was 69.6% in patients with positive parametria and 84.9% in patients without parametria involvement. Further analysis also revealed a 69.1% DFS in patients with margins involvement and was 84.3% in patients with negative margins (Wu et al.). An increasing number of studies have provided evidence of less-radical surgery in patients with stage IA2 and IB1 disease (Bouchard-Fortier et al., 2014), in whom the risk of parametrial involvement is approximately 2% and 6% to 10% respectively. The risk pelvic lymph node metastases are less than 15% (Frmovitz et al., 2009).

Barriers to cervical cancer treatment and management have been a significant issue in LMICs, and researchers around the world over the years have conducted studies that aim to reveal barriers to cervical cancer management from the economic perspective of patients and availability of resources in many LMICs. Lori et al. conducted a study in 2012 to identify some of these barriers and facilitators to cervical cancer screening, diagnosis, follow-up care, and treatments among human immunodeficiency virus (HIV)-infected women and clinicians and to discover the tolerability of patient navigators in Tanzania (Lori et al., 2018). Outcomes from their focus groups indicate the prevalence of fear and stigma surrounding cervical cancer as well as lack of information and access to treatment and screening. It was identified in the clinician focus groups that there were numerous barriers to screening, diagnosis, follow-up care, and treatment. Participants agreed that in both types of groups that a patient navigation program would be an effective way to help women navigate across the cancer continuum of care, including screening, diagnosis, follow-up care, and treatment (Lori et al.). Investigating socio-demographic characteristics influencing cervical cancer screening intention of HIV-positive women in the central region of Ghana, Ebu conducted a descriptive cross-sectional study involving a convenience sample of 660 HIV-positive women aged 20 to 65 years receiving antiretroviral therapy in HIV care centers in the Central Region of Ghana was conducted using an interviewer-administered questionnaire. The study revealed that 82.0% of HIV-positive (Ebu, 2018) women intended to obtain cervical cancer screening. The level of education was a determinant of cervical cancer screening intention. HIV-positive women with low levels of education were 2.67 times (95% CI, 1.61–4.42), more likely to have the intention to screen than those with no formal education. Those with high levels of education were 3.16 times (95% CI, 1.42–7.02), more likely to have the intention to screen than those with no formal education. However, age, religion, marital status, employment status, and the ability to afford the cost of cervical cancer screening were not determinants of intention to screen (Ebu, 2018).

A study using a mixed methods design was conducted in Zimbabwe to investigate the determinants of access to treatment and care among women with cervical cancer in Harare. Three surveys, including community, patient, and health worker surveys, were conducted with a sample size of 143, 134, and 78 participants respectively in the first phase (Tapera et al., 2019). Validated structured questionnaires programmed with an android tablet with ‘Survey to Go’ software was used for data collection during surveys. Knowledge of causes (p=0.046), perceptions of the adequacy of specialists ($p < 0.001$), locus of control ($p = 0.009$), service satisfaction ($p = 0.022$) and walking as a means of reaching nearest health facilities ($p < 0.001$) (Tepera et al., 2018) were associated with treatment or perceptions of access by healthy women.

Perceptions of access to treatments among health workers were associated with their fundamental training institution (*p* = 0.046), health service quality perceptions (*p* = 0.035), and electricity supply status in their respective health facilities (*p* = 0.036). Qualitative findings revealed health system, societal, and individual factors as barriers to accessing treatment and palliative care (Tapera et al., 2019).

Addressing these issues is critical due to the high incidence of cervical cancer rates in Ghana. According to the World Health Organization (WHO) (2018), the high rates of chronic comorbidities and infectious diseases such as the HPV virus, which a significant cause of cervical cancer, are also contributing factors. When combining this with a lack of access to adequate health care services, routine screening, and vaccination in the African region, there are significantly higher rates of preventable disease (World Health Organization, 2018). While the Ghana government adopted VIA as part of the National Cervical Cancer Prevention Program, rural communities still do not have access to doctors and hospitals when needed. This can be due to costs, lack of information, or personal beliefs (Sanghvi et al., 2008). Drislane et al. (2014) pointed out that high-quality medical care, access to medical facilities, and care remain a considerable challenge. Also, costs are high for both patients and the facilities. Medical facilities are still short-staffed, and medical costs were becoming too costly to maintain for proper diagnosis, treatment, and management planning.

Societal Level Barriers

Cervical Cancer Prevention Programs

According to Finocchario-Kessler et al. (2016), the World Health Organization is recommending a national immunization program that will provide HPV screenings and vaccine delivery to individuals that would be cost-effective. Additionally, up to 2014, HPV vaccines were only seen in more developed countries (58), that provided sufficient access to the HPV vaccine. Countries like Lesotho, Uganda, Rwanda, and South Africa had introduced a national HPV vaccine to its citizens (Finnochario-Kessler et al., 2016). Because countries in sub-Saharan Africa are underdeveloped and lack prevention resources, screening and educational interventions are very important that focus on cervical cancer awareness, signs symptoms, and the importance of screening. Furthermore, most women only seek help when they are already experiencing symptoms, which results in delayed diagnosis and increased risk of mortality (Stewart, Moodley, & Walter, 2018).

Efforts have been made to increase access to HPV vaccines, increasing pap tests, and educating women on the importance of obtaining both. Black and Richmond discussed the challenges with expanding this effort in Africa, stating that “implementing screening programs in [Sub-Saharan Africa] has so far proven to be challenging due to financial, logistical, and sociocultural factors” (2018, p. 61). The World Health Organization (WHO) indicates that HPV infections account for approximately 68,000 cases every year in Africa (World Health Organization, 2019), and indicates that even with the HPV vaccines available, access to providing the vaccines have been challenging due to lack of resources. Black and Richmond also stated, “With many Sub-Saharan Africa countries now eligible for Global Alliance for Vaccines and Immunization (GAVI) support for vaccine introduction, it is timely to consider the factors that impede and facilitate the implementation of vaccine programs in Sub-Saharan Africa” (2018, p. 61)., the effort to address cervical cancer, pap test screenings, and HPV vaccines have been available over the years; however, additional efforts are necessary to decrease cervical cancer incidence and mortality. Low levels of uptake have been seen even in African countries like Nigeria where screening was made available, awareness was high, and the educational level of participants was higher than other studies in a similar setting (Okunowo et al., 2018).

Community Health Education and Health Promotion

There are positive attitudes and beliefs among organizations such as the Ministries of Health that evidenced-based cervical cancer prevention efforts are scalable to promote cervical cancer awareness in LMICs. Still, the community, health workers engagement, is also needed. There needs to be a shared responsibility approach in educating individuals and communities in Ghana and other LMICs about cervical cancer by using individuals closest to the community who understand the cultural landscape. Therefore, community health worker engagement was pertinent to ensure the community's perceived barriers were understood and addressed appropriately at each level to educate individuals successfully and ultimately implement sustainable routine screening, mandated healthcare coverage for screening, and HPV vaccination of young girls and boys before their first sexual experience. Efforts to educate policymakers and organizations about necessary resources to ensure individuals, stakeholders must embrace availability and uptake of culturally sensitive prevention, treatment, and management options, and the community at large to improve cervical cancer outcomes among women in Ghana.

In the U.S. and other developed countries, health promotion has increasingly embraced community engagement, defined as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" (Centers for Disease Control and Prevention, 1997, p. 9). In general, the goals of community engagement are to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as research evolve into sustainable prevention and control programs (Center for Disease Control and Prevention, 1997; Shore, 2006; Wallerstein, 2002). This concept can be applied in LMICs such as Ghana by first exploring the perceived barriers at all levels and using the outcomes to tailor specific intervention and prevention measures to the Ghanaian community needs. The rationale for assessing the Ghanaian cervical cancer patients, healthcare professionals, and other stakeholders in their natural setting is because social norms, behaviors, and the incidence of delayed detection and diagnosis of cervical cancer are all influenced by social and physical environments that make up the community in which they live (Hanson, 1988; Institute of Medicine, 1988). Understanding the influence at each level beyond the individual social and behavioral determinants of health are required to develop sustainable prevention, treatment, and management plans to ultimately decrease incidence and mortality due to cervical cancer among women in Ghana.

In addressing prevention, a multi-level approach is necessary to disseminate information to the people in LMIC countries such as Ghana. One study suggested dissemination of educational information to those who live in the countries is to educate teachers and administrators about cervical cancer causes, signs and symptoms, the Pap test, and routine cervical cancer screening (Nartey et al., 2018). Additionally, preventing cervical cancer must involve community health workers to educate women who would not be reached in the school systems, as well as providers conducting a visual inspection with acetic acid (VIA) or conventional Pap testing, which is difficult due to access and cost of medical services (Williams-Brennan et al., 2012).

Community Health Services, Advocacy Groups, and Support Programs

One of the social determinants that contribute to the late-stage presentation of cervical cancer is access to health facilities and health care. As mentioned earlier, Africa has limited resources, and many people in various countries in Africa do not have access to adequate medical care or medical facilities, especially in Ghana. This presents a barrier to educating and implementing prevention measures. A study conducted on Kenyan women 15 years or older examined the uptake of cervical cancer screenings in Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH), where a cervical cancer screening program has been implemented. Despite the program being implemented, only 3.2% of women were screened for cervical cancer (Morema et al., 2014). A cross-sectional study was conducted that examined the knowledge, perceptions, and cues for action among women receiving cervical cancer screenings (Morema et al., 2014). The study also collected data regarding socio-demographic statuses and analyzed the statistical significance using chi-square to identify the determinants in the uptake of cervical cancer screenings.

The results of the study suggested that there were positive associations between age, income, and uptake of services and that the perceived susceptibility was a determinant in being screened. However, for those with less financial ability were not able to seek medical attention, pay for the costs of medication, costs associated with travel to the hospital, or cost of diagnostic testing (Owenga & Nyambedha, 2018). Additionally, many who were referred to JOOTRH did not have medical insurance to cover the hospital stay and could not receive assistance from the National Hospital Insurance Fund as it only covered inpatient procedures (Owenga & Nyambedha, 2018).

Cervical Cancer Screening and HPV Vaccination Mandates

Access to medical care and medical facilities is a challenge in Africa due to the location and costs of medical services. This poses a concern for the prevention of cervical cancer through Pap screens due to distance to a tertiary facility and the cost of covering the Pap tests. There is a need for additional financial resources to encourage prevention and HPV vaccines. The healthcare system in Africa needs to broaden its scope of access to include LMICs to access services and provide continued financial support for women to obtain cervical cancer screenings.

LMICs have a pressing need for mandated routine screening, HPV vaccination, sex education and cervical cancer awareness among school-aged boys and girls Although the prevalence rate of cervical cancer is high, the rate of cervical cancer screenings in LMIC populations has remained low, with various contributing factors making it challenging to provide knowledge regarding screening services. As a result, organizations such as the Ministry of Health seek to increase the knowledge regarding HPV vaccines and cervical cancer utilizations (Kangmennaang et al., 2018; Ngcobo et al. (2019) examined the hesitancy and acceptance of HPV vaccines in South Africa. The study discussed how implementing policies in schools to educate students on the risks of HPV could increase the uptake of HPV vaccines. The study shed additional light on the need for community health workers in South Africa to also engage in the necessity of educating populations about HPV vaccines, while also performing comprehensive cervical cancer screenings. The researchers noted that, despite resources from organizations to increase knowledge and utilization for HPV vaccines, policies need to be created and supported by local research that includes:

- Policies surrounding the necessity of HPV vaccinations, including the recommended age of dosage;
- Communication to the public, unusually public and private sectors, schools, and parents, that focus on HPV vaccinations in adolescent school-aged girls and boys, based on the recommendations for adolescent in the United States from the CDC and the U.S. Preventive Services Task Force;

- Onboarding the Department of Education to assist in advocating for HPV vaccines and cervical cancer screenings;
- Operating procedures for community health workers and their role in educating and promoting Pap tests, HPV vaccines, and early diagnosis of cervical cancer. This would also include medical providers, practitioners within the school setting, and tertiary clinics;
- Addressing the cost and access associated with high-risk populations in seeking medical treatment and management for gynecological services; and
- Increasing prevention and screening among those with medical insurance who can afford the HPV vaccine (Ngcobo et al., 2019).

Comprehensive Healthcare Coverage

Further implementation of policies surrounding access to care associated with prevention, treatment, and management of cervical cancer is necessary to address the high-risk populations.

Nartey et al. (2018) examined initiatives implemented to increase cervical cancer screening by analyzing policies and resources available in Ghana using a multi-level approach. One recommendation was to implement a national cervical cancer policy to include “policy development, program management structure, planning and preparation, implementation, monitoring, and evaluation” (p. 95) and include resources for community health workers and schools to include “prevention, early detection, treatment, and palliative care” by utilizing the National Cancer Control Strategy for Ghana as a reference (2018). The researchers conducted a qualitative study in which they developed a structured questionnaire for the women, and then an assessment of HPV abnormalities and detection was performed to determine if HPV was present. The questionnaire was used as a telephone interview. After that, a study was performed, along with a review of medical records, phone interviews, and incidence, mortality, and survival rates obtained after diagnoses. Knowledge regarding cervical cancer screening and HPV was low among the women, both within and without presentation; however, those who presented as well educated had more knowledge of the risks surrounding cervical cancer.

The researcher’s study will utilize a semi-structured interview method, key informant interviews, and focus groups, whereas the study utilized a structured questionnaire. Bernard (2000) described the main differences between a questionnaire and an interview. The first difference is that a questionnaire is a process of collecting information from a large group of individuals, whereas an interview is used to collect information from smaller groups. Second, the interviews are more flexible. The interviewer can adapt to meet the flow of the interviewee. Third, it is essential to remember that questionnaires are generally quantitative versus qualitative. Quentin et al. (2011) investigated the importance of scale in costs of cervical cancer screening and treatment using visual inspection with acetic acid (VIA) and cryotherapy in Ghana. Incremental economic costs of VIA and cryotherapy were estimated in two steps using an ingredients approach: (i) quantities of resources used were measured, and (ii) unit costs or prices were assigned to resources consumed. According to the study, it was suggested that

As the scale is an important determinant of costs, policymakers in Ghana and elsewhere should aim to increase the number of women screened per facility. To do so, demand-side barriers such as user-fees, which were introduced at Ghanaian screening facilities after discontinuation of external support, should be removed and replaced by continued public funding. The availability of services needs to be assured as non-functional cryotherapy machines are discouraging both providers and clients. Investing in recruitment/mobilization campaigns becomes important to make efficient use of resources. Approaches to integrating screening in family planning clinics appear useful, as they allow easy recruitment of women attending such services. At the same time, women receiving screening can benefit from the treatment of vaginal infections detected during the visual inspection. (Quentin et al., 2011, p. 384)

Government-sponsored Sex Education Programs

In Ghana, there is a lack of comprehensive sex education among school-aged adolescents, both boys, and girls, who should be receiving their HPV vaccines as early as age ten before their first sexual encounter (World Health Organization, 2019). Policies geared towards the implementation of comprehensive sex education will introduce cervical cancer awareness and HPV risk early on and meet the same standards that the CDC has set for adolescent girls and boys in the U.S. (World Health Organization, 2018). Furthermore, cost-efficient, evidence-based programs can be successfully implemented in schools, churches, and health facilities, through encouraging mandated educational intervention, routine screening, and HPV vaccination by policymakers and thought leaders in Ghana. Additionally, policies providing resources and requiring community health workers, providers, and other clinical staff to obtain the knowledge and educate and encourage cervical cancer screening may also assist in decreasing the incidence and mortality rate associated with advanced-stage cervical cancer presentation. Understanding the perceived barriers to early detection, diagnosis, and treatment of cervical cancer could lead to improved targeted measures to ultimately decrease morbidity and mortality associated with the disease in Ghana.

Utilization of the SEM for Cervical Cancer Research

The SEM provides a multi-level approach to addressing the health concern in women who are at high risk of infection and addressing the perceived barriers to timely detection, diagnosis, treatment, and management of cervical cancer. By examining the perceived barriers and suggested strategies to overcome barriers, alternative methods may be developed. Several studies have been done utilizing SEM.

A study conducted by Nyambe et al. (2018) assessed how sociocultural and political environments view cervical cancer, and the goal to expand cervical cancer prevention services. The study took a qualitative approach by conducting interviews with stakeholders (which included health providers, teachers, and religious leaders), special interest groups (including non-governmental organizations and advocacy groups), and policymakers in Zambia. The study took a multi-level approach by utilizing the socio-ecological framework, along with the Theory of Triadic Influence, to analyze the issue from “multiple ecological levels of influence,” including intrapersonal, interpersonal, policy, community, and organizational (Nyambe et al., 2018). Nyambe et al. used factors from the SEM that were similar to the method the researcher will use for the current research study, including examining the Organizational structure of social institutions, special interest groups, and policymakers. Also, Nyambe et al. focused on several key factors that are also relevant to the current study including the availability of services, failing schools, information opportunities, interaction with social institutions, vaccination and screening, stigma, knowledge, values, religious beliefs, cultural norms, age recommendations, and the vaccination of both sexes (2018). Nyambe et al. (2018) conducted a two-step sample to select the institution and participants for the study who had prior knowledge about cervical cancer. The results obtained from the study concluded that cervical cancer prevention was a result of “policy, availability or lack of facilities and services, and information sources and knowledge”. From this, recommendations were presented to address cervical cancer prevention through the expansion of the vaccination, policies, and access to health facilities and services.

Another study by Palafox et al. examined the organizational structure using the SEM for addressing cervical cancer in the US Affiliated Pacific Island Jurisdictions (USAPIJ) by discussing the five frameworks and their contribution to cervical cancer outcomes. Palafox et al. stated that the external partner, the Pacific Regional Cancer Control Partnership (PRCP), was developed to analyze and address cancer prevention (2018). The PRCP utilized the SEM to "contextualize its typology, building blocks, and management" over a 12-year community case study. The study identified internal as well as external factors that contribute to addressing cancer concerns on a broader to narrower scale. The study provided an example of the multifaceted approach to addressing cervical cancer as it relates to delay in diagnosis and prevention measures for women in Ghana. The study is useful as a similar example as the PRCP is isolated and have limited health resources. SEM was used to examine the individual, interpersonal, organizational, community, and policies that are the foundation socio-ecological framework. (Palafox et al., 2018). The internal structures were found to be comprised of diverse levels of community members, including cancer survivors, their family members, clinicians, local government, national government, public health workers, educators, and faith leaders. The external structure is "where the international, academic, advocacy and extra-mural funding organizations work to support the planning efforts of the internal structure" (Palafox, 2018, p. 315). Policy organizations influence, develop, determine, and interpret relevant health policies. Technical assistance and funding agencies such as the CDC and NDI, aid in both research and funding (Palafox, 2018).

Nyblade et al. (2017) conducted qualitative studies of cervical and breast cancer using SEM in Karnataka, India. The two cancers were studied as separate studies. The cervical cancer study had 147 participants from two rural areas. The interviews were semi-structured and lasted from forty-five minutes to an hour and a half. The topics for the interview included cervical cancer awareness, knowledge of the risk factors, symptoms, prevention, and treatability, if they knew where they could find information sources, barriers to cervical cancer screening, knowledge of screening procedures, levels of comfort going to the screening and talking about screening and cervical cancer symptoms, reasons for not getting the screening, willingness to be screened in the absence of symptoms, stigma, and shame and embarrassment (Nyblade et al., 2017). The results of the study suggested that stigma was one of the biggest reasons for not discussing or getting a screening.

Binka et al. (2019) conducted a study that sought to explore the barriers to the uptake of cervical cancer screening and treatment in the North Tongu district of Ghana. The study included three focus group discussions and twenty-five semi-structured interviews among women with and without cervical cancer. Findings showed a low level of knowledge about the disease and screening services, personal or psychological convictions, and the cost of screening and treatment coupled with a low level of income were the barriers at the individual level. Perceived health personnel attitude, perceived lack of privacy, and misdiagnosis were barriers at the institutional level. At the same time, the sociocultural belief system of the communities about the etiology of the disease was the barrier at the community level. Inadequate education about the disease, lack of funding, and access to screening facilities also constrained screening and treatment at the policy level (Binka et al., 2019). The study concluded that cervical cancer screening and treatment are constrained at multiple levels in rural Ghana. (is study underscores the need to address the low uptake of cervical cancer screening and treatment at the individual, community, institutional, and policy levels simultaneously.

Four studies were discussed that used the SEM framework and can be foundational for the current study. Each study has strengths and weaknesses that affect how the researcher viewed the study as a reference for the methodologies for the current study. Nyambe et al.'s (2018) study used participants who already had an awareness of cervical cancer. This awareness is a weakness based on the current study, as many Ghanaians are not educated regarding cervical cancer. Participants are unlikely to understand the disease or even how important prevention is for them. The strength of the study was that the researchers examined all the stakeholders. By examining all of the stakeholders, the researchers could better identify the gaps in the system.

Palafox et al. (2018) used the SEM structure to focus on the internal structure, the external structure, the policy organizations, and the technical assistance and funding agencies. By examining each structure as a separate identity, the researchers were able to examine how the structures affected one another. The study examined a 12-year history of cervical cancer patients. The main strength of the study was the breadth of the study by using the 12 years of patient data. On the other hand, changes occur quickly in the medical field and technology. Therefore, the early years may not be relevant and affect the outcomes.

Nyblade et al. (2017) study shared several common attributes to the researcher's current study. The study was conducted by examining the five levels of the SEM framework and several factors (as mentioned above) that affect participants. Several of the factors are considered in the current study. The one major weakness of the study was that too many factors were examined. When examining such a huge list, it is often difficult to determine which factors are most important, especially in a qualitative study.

The final study by Binka et al. (2019) was also very similar to the researcher's current study. The study was conducted by condensing the SEM into four levels. The researcher considered several of the same factors in the current study. The study was conducted in the same country as the researcher. One major strength of the study is that the researchers interviewed women with and without cervical cancer. The researcher's current study, including health professionals, is one major difference that can lead to additional barriers and strategies to improve cervical cancer care at the different levels of the SEM. Also, the researcher's current study includes the five levels of the SEM, whereas Binka et al. study combined the interpersonal and intrapersonal levels.

Summary of the Chapter

In summary, there were several factors identified as barriers to cervical cancer timely detection, treatment, and management in the literature at the various levels of the SEM. Also, a few studies provide methodological insight into the application of the SEM to cervical cancer research. The findings from this literature review were utilized to inform the development of the interview guides and analysis plan for the current study, which will be discussed in the next chapter.

CHAPTER 3

METHODOLOGY

Introduction

This chapter provides an overview of the methodology utilized to conduct the study. Given the exploratory nature of the research, a qualitative study design consisting of primary data collection via semi-structured interviews and focus group discussion was used. It is crucial to understand the perceived barriers of early detection, treatment, and management of cervical cancer from the perspective of the local population in Ghana. Therefore, cervical cancer patients and their healthcare providers are included in the study.

Study Design

Qualitative research is vital in decision making, policy development, implementation, and evaluation of diseases such as cervical cancer (Trochim, 2015). Scientific literature has proven that the prevention of cervical cancer through HPV vaccination can lower incidence in LMICs. Early detection of pre-cancerous cervical lesions and invasive cervical cancer can be successfully treated and, in most cases, cured. There are multifaceted, interrelated barriers to uptake and implementation of these recommendations in Ghana and other LMICs. Very little evidenced-based literature is available on the perceived barriers at multiple levels of the social-ecological model (SEM) beyond the individual/intrapersonal level to understand better the relationship between the levels and its effect on the cervical cancer timely diagnosis and treatment outcomes. A clear understanding of this complex interaction is needed to be able to develop sustainable cervical cancer prevention and control programs that improve cancer awareness, health-seeking behavior for women in Ghana, early diagnosis/detection, treatment, and management practices. This is especially important in the absence of formal routine screening and mandated policies and programs. Most studies that have been conducted that look beyond the individual/interpersonal level have been conducted in developed countries.

Qualitative methods are effective at identifying intangible factors such as an individual’s knowledge, attitudes, and beliefs about a specific disease or disorder. The social and cultural norms, gender roles, and perceived barriers to behavioral and social change at the organizational and societal levels can also be identified for the target population. Understanding these factors in the target populations' natural setting is needed to develop sustainable and scalable intervention programs to prevent advanced stage cervical cancer presentation and provide adequate treatment and management for women in Ghana.

Site Selection

This study was conducted at Komfo Anokye Teaching Hospital (KATH), a tertiary teaching and referral hospital established in 1975. The facility currently has over 1200 beds. The hospital is in Kumasi, the second-largest city and the capital of the Ghana Ashanti Region. Kumasi is in the transitional forest zone and is about 270 km north of the national capital, Accra, and has an area of about 254 square km. The indigenous people are Ashanti’s, and their primary occupation includes trading and farming. The local dialect of the Ashanti’ is Twi (local Ghanaian language). Kumasi is cosmopolitan and has drawn migrants from all over the country and from abroad. Other ethnic groups include Fantes, Dangomba, Frafra, Hausa, Ewe, Ga Adangbe, and Krobo. There are nine sub metros in Kumasi, including the Bantama Sub Metro, where KATH is located. It is the only tertiary hospital in the Ashanti region and the main referral hospital for the northern sector of the country.

The oncology unit of the KATH was the primary location for the recruitment of women with cervical cancer and the health care professionals that provide care and services to them. The oncology unit is the only national radiotherapy center in the Kumasi Metropolis and the northern part of the country that sees and treats cancer patients. The hospital ‘s radiotherapy and nuclear medicine (Oncology Department) was commissioned in 2004 and are still operational. Cancer treatment services are given to clients with malignant tumors and hematological cancers. The center sees and treats about 775 patients annually. Cervical cancer is currently the most prevalent type of cancer treated at KATH. The treatment options offered at KATH are chemotherapy, hormone therapy, radiotherapy, and brachytherapy. The center also sees referral cases from neighboring countries such as Côte d'Ivoire, Togo, Nigeria, and other African countries. Patients from neighboring countries were excluded from this study to avoid differences based on geographical regions.

Participant Sampling and Selection

A non-probability purposive sampling frame methodology was used to select the target population. Two KATH oncology unit staff led the recruitment efforts with the assistance of nurses in the oncology unit. Recruitment was ongoing throughout the data collection period, July 2019 – August 2019. The final number of participants was determined by the point at which *saturation* was reached, meaning the same ideas and themes are being repeated, and no new information was being identified (Charmaz, 2005). Recruitment ended for each shortly after saturation was reached, but any patients recruited were still interviewed because of the lag time between recruitment, interview, and transcription of the interview.

Heterogeneity Nonprobability Sampling

Women with cervical cancer were recruited and asked to participate in the study. Inclusion criteria that the patients were required to meet were 18 years of age or older, lived in Ghana, and had a documented diagnosis of stage I-IV cervical cancer (See Appendix A. FIGO, 2019).

Expert Nonprobability Sampling

Two oncology unit staff were used to recruit health care professionals to participate in in-depth interviews or focus group discussions. The oncology directorate informed staff about the study during the monthly staff meeting providing them with study details derived from the study consent documents. Their leadership assured the staff that it was okay to take time from their daily work to participate in the study, and their responses were confidential. Staff were solicited for participation based on their experience providing health care support, resources, health promotion, and education for cervical cancer patients. The categories of health professionals recruited for participation included unit directors, physicians, nurses, benefits administrators, social workers, community organization leaders, and other healthcare professionals who provide services to cervical cancer patients. Whenever feasible, two or more health professionals were recruited from each professional category.

Ethical Issues and Implications

CITI Training was completed by all researchers working on the study before the start of the study. This ensured that everyone was trained on privacy, confidentiality, and ethical considerations for vulnerable populations (women and low-income) in research that includes human subjects. Given that the study was conducted in the underserved population in an international setting, a full Institutional Review Board (IRB) review was requested. All ethical issues for vulnerable populations were taken into consideration. This study was originally approved by Georgia Southern University IRB number (H16458) on 8/15/2016 and amended on 7/15/2019. KATH research and development unit certificate of registration number (RD/CR19/180) was amended for the current study on 7/12/2019 and Ghana Committee on Human Research, Publications, and Ethics approval reference ID (CHRPE/AP/444/18) was issued on 7/19/2019. Participants were provided with a recruitment letter that documents the purpose of the research and provides them with contact information should they have additional questions. Each participant completed a consent form before participation. Due to the sensitive nature of the disease, all women with cervical cancer were interviewed via semi-structured interviews. Semi-structured interviews were administered to participants in the conference room or office location at KATH to ensure privacy. Participants were advised that the study is voluntary, and they may withdraw at any time throughout the study without penalty. Prearranged emotional support via psychiatric counselors at KATH was made available, but no patients required this support during the study. Additional precautions were taken to work with the oncology staff to ensure that late-stage cancer participants' progression of disease and stability had not reached a critical level that the study would be considered above minimal risk to the participant.

Data Collection Process and Procedures

Training

Careful training is required for standardization of data collection procedures and emphasizes adherence to studies documented processes and procedures to ensure data quality without compromising ethical issues (Szklo, 2014). Each member completed the CITI IRB training before the start of data collection and familiarized themselves with the approved IRB to ensure the safety and confidentiality of all human subjects. Interviewers, note-takers, and translators participated in a full two-day training on all study materials used for data collection, including but not limited to recruitment protocol, interview guide/probes, note-taking, and data transcription/recording to minimize interviewer bias. All study staff received an overview of the studies, purpose, methods, and intended outcomes during the training and were allowed to ask questions and speak on any concerns they may have. Mock interviews were conducted by the interviewers on each other and other KATH research staff to become more familiar with the interview guide and probes.

Pre-test and Pilot Testing

Pre-testing and pilot testing, followed by data collection, occurred approximately June 2019 – August 2019. Data collection instruments for cervical cancer patients were developed in English and translated into Twi (Ghanaian language). Instruments were pre-tested and reviewed by two Ghanaian health professionals, four Ghanaian third-year medical students, three GSU faculty members, and two GSU doctoral students to ensure cultural sensitivity and to detect significant flaws before pilot testing. Pilot-testing was conducted on a small sample population of participants with cervical cancer (n=2) and health professionals (n=2) at the study site in Ghana. The pilot test helped us gain insight into the need for refining the research questions and methods before conducting the full research study. The pilot test included the introductory questionnaire, study research questions, interview guides, and probes. After doing a pilot study and piloting instruments, certain aspects of the design and interview guide/probes were modified as needed. Sensitive questions were removed from the introductory questionnaire (HIV status). Throughout data collection, an iterative process was used to refine the interview guide/probes further as required to ensure interview questions/topics were easily understood and yield the intended data outcomes. The interviewers fluent in English and Twi participated in the pilot study to ensure that any discrepancies between Twi and English language translation were discovered before the start of official data collection. The instruments were updated accordingly. The pilot test participants were included in the final dataset. Responses were consistent with data collected during the data collection phase.

Recruitment and Informed Consent

Two KATH oncology unit staff, the Georgia Southern University community liaisons, and Ghanaian medical students all contributed to recruitment efforts. The use of the professional team for previous research studies at KATH has been documented in the literature to ensure the smooth recruitment of participants (Asoogo et al., 2015). Using hospital staff for recruitment of early and advanced stage cervical cancer participants made it easier to verify the stage at diagnosis and the patient's physical and mental stability to participate. Women in critical condition such that participation was considered above minimal risk physically or emotionally were excluded. Individuals presenting with diagnosed mental illness or issues such as speech and hearing that made communication difficult were also excluded.

After the researchers introduced themselves, a brief overview of the study was provided to each participant before starting the interviews. Participants were informed that their participation was voluntary and that they could withdraw at any time from the study without penalty. A consent form was completed by 100% of the participants (Appendix B and C). Participants were asked for permission to record their interviews as part of the consent process. Participants were advised that the recording was for quality assurance purposes to ensure accurate documentation of their statements, and only researchers who are a part of the study would have access to the data. Only one participant (1/69) refused to record the interview. A third researcher was added to the interview to assist the note taker with field notes to ensure the verbatim capture of the participant's responses. One recording was lost, and another consisted of inferior quality. The three interviews without recordings were transcribed from the researcher's interview notes.

Data Collection

Introductory Questionaire. A socioeconomic and demographic characteristic questionnaire was administered to cervical cancer patients before the start of the interview to provide insight on the participant population. The questionnaire consisted of 21 questions, including basic demographic questions, family history of cancer, and questions related to known risk factors and behaviors associated with cervical cancer (Appendix D). A nine-question introductory questionnaire was also administered to health care professionals to gain insight into the respondent's healthcare experience, the patient population served, and basic demographic characteristics (Appendix E).

Semi-structured Interviews and Focus Group Guide. A semi-structured interview guide and probes were developed to explore issues that cross the five levels of the SEM individual, interpersonal, community, organizational, and societal (Appendix F and G). The interview guide and probes were created using qualitative interview guides and quantitative questionnaires from peer-reviewed studies conducted in a similar setting. The interview guide and probes were used to facilitate the conversation and ensure that all core concepts were covered during the interview. There was no formal questionnaire instrument. No specific sequence was followed, but all core concept was addressed at some point during each of the interviews or focus group discussions. This allowed the participants to answer in their own words briefly or with a detailed response, with little influence from the interviewers. Focus groups can allow for a larger quantity of participants at one time, thereby potentially increasing the sample size that can be captured in a shorter period. Due to the sensitive nature of the disease and potential social and cultural stigmas associated with cervical cancer, semi-structured interviews were conducted for all patients with cervical cancer (n=38). Focus groups were offered to health professionals, but the majority of the health professionals (n=25) preferred individual interviews. Two focus group discussions were carried out during the study data collection. One focus group discussion consisted of four nurses. Another focus group discussion included two staff working in the oncology unit.

Incentives

Each participant was given 25 Ghana cedi for their participation, which is equivalent to approximately 5 USD. All participants were made aware that they would still be given the 25 Ghana cedi's even if they decided to end the interview early. Participation in the study was voluntary. Only one cervical cancer patient participant (1/38) started the interview and ended before completion. The participant still received the incentive.

Data Analysis and Software

Qualitative data analysis software NVivo12 for Windows was used to assist with transcription analysis, coding, text interpretation, and describing of meaning units discovered in the analyses when appropriate. NVivo12 was also used to organize, retrieve, and present the data effectively and more coherently via concept mapping. SPSS statistical software was used to analyze the introductory questionnaire and provide descriptive statistics for the respondent population.

Theoretical Thematic Analysis was chosen as the method because it allows for the identification and reporting of patterns, also known as themes within the data. Thematic analyses also can connect patterns into meaningful themes that can be translated into public health implications. Qualitative analysis of perceived barriers and strategies for improvement from the patient and the healthcare professional perspective in Ghana was not seen in the review of the literature. Therefore, the thematic analysis provided the opportunity to find new themes that mapped to the different levels of the SEM through the extensive data gathered from the semi-structured interviews and focus group discussions that can add new findings to scientific literature. The SEM was utilized to help understand how each level factors interact together to influence health-seeking behavior. The model was also used to help interpret the perceptions and experiences of cervical cancer patients and health professionals. Socioeconomic and demographic characteristics of each participant were obtained at the start of the interviews to provide additional context for the participant population. Data were analyzed using SPSS statistical software.

Theme Development Process

Phase I Familiarization with the data. Getting familiar with the data by listening to recordings, reviewing notes, read, and re-reading transcriptions to understand better the content and extent of data collected was a significant first step to data analysis was the first step. The transcripts were read several times by two researchers to gain a clear understanding of the whole experience to identify descriptions of meaning units, which are small segments of a transcript or other text that captures a concept that the researcher deems to be significant (Trochim, 2015). Audio recordings were reviewed multiple times by two different researchers speaking fluent English and the native language for participants to ensure that transcription was as accurate as possible and for researchers to become familiarized with the data meaning units as heard from the respondents. Notes were taken during each interview to ensure that different nuances that were not captured in recordings such as (facial expressions, tone, body language, position, etc.)

were reviewed. Relevant notes were included in transcriptions to give additional context to participant responses.

Phase II Generating initial codes. The coding of the initial codes was based on the interview guide, but new codes were added that emerged from the data. The codes were developed and modified as the researchers worked through the full coding process. The text-based themes were centered around the levels of the SEM and other themes that were discovered throughout the classification of the text. The researchers did not code every piece of text. Each coded segments of data captured something interesting about the actual research question.

Phase III Searching for themes. The SEM was hypothesized as the model for data collection during the design of the study. Therefore, coding and theme development were directed by the assumptions and concepts of the hypothesized model. Each of the initial codes was analyzed to generate additional themes. Themes are considered ‘latent’ themes, which are seen across the majority of the data set (Clarke & Kitzinger 2004). Coded data were also analyzed qualitatively in NVivo 12 to determine what words occurred most frequently, in what contexts, and how they correlated. Themes were indexed into a list of key ideas in a matrix format. Word clouds and word trees were developed to compare the researcher's initial coding scheme.

Phase IV - V Reviewing Themes and Defining and Naming Themes. A combination of the themes extracted from both health professionals and patients were reviewed. Related themes were merged to form a more significant theme. The overall themes (merged) were named to describe the data discussed in each of the themes. Emergent themes were tested by reviewing the data to determine if there were any negative occurrences of the patterns. These were considered outliers and investigated to determine if they were truly outliers or lead to additional concepts/themes. Themes were based on importance to the overall research question versus the number of times it appeared within the data set (Clarck & Kitzinger, 2004).

During the analysis phase, findings were reviewed to determine if there was any researcher effect due to differences in age, gender, language, and nationality that influenced the outcomes. Themes derived from patients and healthcare professional's data were consistent across interviewers regardless of age, gender, and language. Reflexivity was used throughout the data collection phase by the supervision of interviews by primary researcher and self-checks by the primary researcher with an adjustment being made throughout data collection and the analysis process.

Phase VI Producing the Report. Themes were defined, and sub-themes further refined for presentation in the analysis report. The relationship between the different parts of the data was assessed to draw clear and explanatory conclusions centered around the themes and sub-themes at the various levels of the SEM.

Validity and Reliability

In a qualitative study, validity means that the results truthfully reflect the concepts studied, and reliability requires that the same results would be obtained if the study were replicated (Morse & Richards, 2002). The integrity of qualitative data is usually judged by four well-known criteria: credibility, applicability, dependability, and confirmability (Leininger, 1994). This section discusses the steps taken to ensure the study's validity and reliability. Validation of the Findings occurred through triangulation, member checks, external validation of coding scheme through independent researcher, documentation of any limitations beyond the researcher/interviewee's control.

Credibility or Trustworthiness is an assessment of internal validity in qualitative research. It is achieved by clearly documenting the purpose, methodology, procedural decisions, and details of how the data is generated and managed (Kitto et al., 2008). All data processes and procedures are outlined in this chapter. Efforts were made to ensure credibility or internal validity through member checking during pilot-testing and through the use of a sub-set of participants during full data collection when feasible. Member-checks were also performed immediately at the end of the interview by the primary researcher and research assistant fluent in the native language. All researchers debriefed to discuss any concerns with questions or participants' perception of the questions we were asking. All discrepancies were resolved, and questionnaire/interview guides were revised accordingly.

During the pilot testing and first few interviews, it was noticed that patients' body language shifted when demographic questions about sexual partners, age at first sexual encounters were asked when the interviewer was male and of younger age. The researchers began allowing the female interviewers to ask sexual behavior questions, and patients still seemed somewhat uncomfortable. It was noted that due to social norms, sexual questions are considered sensitive in African culture. Data collected were compared to patient records whenever available and were found to be highly consistent regardless of the gender of the interviewer despite the level of discomfort visually noted. Due to the sensitive nature of the questions, many respondents refused to answer or said they did not remember.

Transferability of Applicability is the assessment of external validity in a qualitative study and was achieved through sampling multiple types of participants (women with early-stage cervical cancer, women with advanced-stage cervical cancer and health care professionals from different specialty areas) based on the SEM levels to gain maximum insight into barriers to early detection, diagnosis, treatment and management of cervical cancer (Hammarburg et al., 2015).

Dependability or Consistency is used to evaluate the reliability of a qualitative study (Morse and Richards, 2002). Each researcher kept a separate journal to document impressions, early interpretations, and changes that occur in the research setting that could potentially affect the conclusions drawn from the interview. Notebooks were reviewed, and information added to transcriptions when applicable. Debriefing sessions with interviewers and researchers were conducted to review notes and interviews daily when feasible.

Confirmability or Objectivity was achieved through researcher verification. Each interview included a facilitator and notetaker in addition to live digital recording. Interviews were conducted in Twi directly with the participant whenever possible to ensure consistency of information captured. Any interviews that used an English-speaking proxy or were conducted in Twi were conducted by qualified professional KATH personnel or third-year medical student who spoke fluent English and Twi. Several interviews included three researchers. Any discrepancies notated in the English to Twi translation were documented and resolved when feasible. When resolution could not be made during the transcription phase after being double transcribed, the data were excluded from results and conclusions. There is always a risk that different researchers draw dissimilar conclusions from the same data. To increase the validity, at least two investigators performed the analysis separately, and the results were discussed, and the consensus was obtained (Burnard, 1991, Graneheim & Lundman, 2004). This procedure is one form of triangulation. To use different sources or methods for data collection are other ways to perform triangulation to confirm the results (Catanzaro, 1988; Patton, 2002; Rolfe, 2006). Therefore, cervical cancer patient and their healthcare providers were interviewed.

Confirmability was also achieved by triangulation using corroborating evidence from interviews, direct observation, verbatim quotations, and clearly outlining the interpretation process (Sandelowski, 1986). Data auditing by the researcher was conducted to examine the data collection and analysis procedures to make judgments about the potential for bias or distortion from researchers' assumptions that they knew what the participant meant to demonstrate confirmability. Transcriptions were double transcribed to ensure that potential bias from researchers' assumptions during the interview was discussed by the independent researcher who was not in the initial interview. The consensus of all researchers was gained to ensure the transcription was verbatim and accurate whenever possible.

Summary of the Chapter

This chapter describes the methods for data collection, analyses, and validation. The inclusion criteria for participants, introductory questionnaire, and the interview guide are also discussed. The next section will discuss the results and the interpretation of the data analyses.

CHAPTER 4

FINDINGS

Introduction

The study aimed to critically examine the perceived barriers to early detection, diagnosis, treatment, and management of cervical cancer in Ghana. The barriers were examined across five levels of interaction, which includes individual level, interpersonal level, community level, organizational level, and the societal level. The social-ecological approach was employed in the study. The SEM hypothesizes that behavior is the result of the knowledge, attitudes, and beliefs of individuals as well as social influences, including the people with whom they associate, the organizations to which they are a part of, and the communities in which they reside. This chapter presents the findings of the semi-structured interview and focus group discussion for cervical cancer patients and their healthcare providers.

Descriptive statistics are presented for cervical cancer participants with detailed information about their age, marital status, trade, income, and education. Additionally, contextual statistics are provided on participants' risk factors such as sexual activities and behaviors (including the age of first sexual encounter), reproductive history, the start of menarche, history of sexually transmitted infection, smoking, and alcohol habit (past and present) (Table 4.1 - 4.4). Descriptive statistics are also presented for health professionals with detailed information on age, gender, religion, marital status, health care experience, and patient population served.

Lastly, semi-structured interviews and focus group data from both participant groups were presented in this chapter. The SEM was used to interpret the results. Themes were supplemented with verbatim text from transcripts. With a focus on ultimately, strategies to improve cervical cancer diagnosis, treatment, and management, this section is organized with a focus on the barriers that emerged from the patients and health providers and the strategies that each group of participants proposed as barrier solutions. The patient and health providers experience has demonstrated that understanding key immediately actionable barriers to timely detection, treatment, and management that provides a pathway to potential opportunities for the development of interventions and societal actions to reduce the barriers and improve health outcomes for cervical cancer patients in Ghana.

Cervical Cancer Patients

Background Characteristics of Cervical Cancer Participants

Thirty-eight cervical cancer patients started the interview, and three patient's data were excluded (one did not complete the interview, and two patients, the researchers were not able to confirm a cervical cancer diagnosis). Therefore, a total of (N=35) patients were included in the data analysis. 14.3% of the sample were aged between 40 and 49 years, while 31.4% were aged between 50-59 years, 54.3% greater than 60 years of age. Most of the women interviewed were from semi-urban areas of Ghana (54.3%), followed by rural settings (22.9%) and urban settings (22.8%). Most participants were secondary school graduates (34.3%), followed by no formal education (31.4%). Less than 10% of the respondents had a tertiary education. A higher percentage of respondents were from low-income families earning GHC 0-600 in a month (82.8%). Middle- and high-income families made up 14.3% of the respondents. 68.6% of the respondents stated they had insurance, but it was inadequate insurance. These findings are consistent with other findings from the literature that shows inadequate, or lack of insurance coverage is high among cervical cancer patients (Dunyo et al., 2018; Nartay et al., 2018). A high percentage of the interviewees were married (37.1%), followed by those who are widowed

(31.4%), divorced (25.7%), and 5.7% are single. This data is consistent with literature that shows high rates of divorce among cervical cancer patients, which equates to a lack of support in a country where men typically care for the women financially (Binka et al., 2019). A high percentage of the sample were Christians (88.6%), followed by Muslims (11.4%) (Table 4.1).

A family history of cervical cancer or other cancers can be associated with higher rates of cervical cancer among patients (Boardman et al., 2019). Table 4.2 displays the results of cervical cancer patient questions about a family history of cervical cancer and a family history of cancer in general. 8.6% of the interviewees had a family history of cervical cancer, and 14.3% had a family history of other cancers. A family history of the disease often may indicate a genetic predisposition for the illness (Boardman et al., 2019).

Questions were asked of the participants about other known risk factors for cervical cancer, including specific sexual activities, tobacco, alcohol use, different behaviors, and practices. The response rate was low on questions that required the respondent to recall things that happened in their childhood or teens and items that could be considered culturally sensitive. Therefore, data may not be as accurate due to recall bias or sensitivity for age at menarche, first intercourse, and number of sexual partners. Data was checked against patient medical records when available. The risk of cervical cancer also tends to increase with higher parity (Boardman et al., 2018; Nartey et al., 2018). 45.7% of interviewees had 4-6 children, 37.1% reported 7+ children, and 17.2% had 1-4 children. Other risk factors the patients were questioned about were the practice of douching and the use of oral contraceptives. 60% of the patients responded that they used oral contraceptives, and 65.7% practiced douching. None of the interviewees reported being a current or former smoker. The majority, 60.0% %, also reported never drinking alcohol, 25.7% were former drinkers, and only 11.4% reported currently drinking alcohol (Table 4.3).

A significant number of patients were in stage 3B of the disease at their initial diagnosis (40.0%), followed by stage 4A with (8.6%), and 2B (7.0%). Stage 1B and 1B2 had 5.7% of the respondents each. Using the FIGO classification (Appendix A), this shows that a little over half (54.3%) of the respondents were diagnosed in an advanced stage and (45.7%) presented in an early stage. Therefore, the data included a representative sample of early and advanced stage cervical cancer participants in the semi-structured interviews. High rates of late staged cervical cancer in this study are consistent with late staged cancer presentation shown in the literature in LMIC (Dunyo et al., 2018; Laryea et al., 2014; Nartey et al., 2018,). Squamous cell carcinoma is the most common cancer in this sample; 94.3 % and 5.7% were diagnosed with Adenocarcinoma, and one patient had spindle cell carcinoma. The squamous cell carcinoma cases included invasive, moderately differentiated, keratinizing, and non-keratinizing squamous cell carcinoma cases (Table 4.4).

Table 4.1: Cervical Cancer Patients Descriptive Statistics

Variable	Frequency (n)	Percentage (%)
Age (in year)		
40–49	5	14.3
50–59	11	31.4
60+	19	54.3
Region of Residence		
Urban	8	22.8
Semi-urban	19	54.3
Rural	8	22.9
Education		
No formal school	11	31.4
Primary school	9	25.7
Secondary school	12	34.3
Tertiary school	3	8.6
Occupation		
Teacher/businesswomen	4	11.4
Seamstress/hairdresser	1	2.9
Table 4.1: Cervical Cancer Patients Descriptive: Continued		
Farmer/trader	27	77.1
Unemployed	1	2.9
Other	2	5.7
Family Monthly Income		
Low (GHC 0–600)	29	82.8
Middle (GHC 601–1200)	5	14.3
(≥GHC 1201)	1	2.9
Insurance		
Insured with adequate coverage for my condition	8	22.8
Insured, but inadequate coverage for my condition	24	68.6
Uninsured	2	5.7
Other	1	2.9
Marital Status		
Single	2	5.7
Married	13	37.1
Divorced	9	25.7
Widowed	11	31.4
Religion		
Christian	31	88.6
Muslim	4	11.4

Table 4.2: Cervical Cancer Patient Family History of Cancer

Variable	**Frequency (n)**	**Percentage (%)**
Family history of cervical cancer		
Yes	3	8.6
No	30	85.7
Do not know	2	5.7
Family history of other cancers		
Yes	5	14.3
No	28	80
Do not know	2	5.7

Table 4.3: Assessment of Risk Factors for Cervical Cancer

Variable	Frequency (n)	Percentage (%)
Age at menarche		
<12	1	2.9
13–14	4	11.4
Above 14	21	60
No Response	9	25.7
Age at first intercourse		
<12	2	5.7
13–17	4	11.4
18 and above	14	40
No Response	15	42.9
Number of sex partners		
1-2	14	40
3-5	15	42.9
>5	6	17.1
No Response	5	14.3
Contraceptive use		
Yes	21	60
No	13	37.1
No Response	1	2.9
Practice douche		
Yes	11	31.4
No	23	65.7
No Response	1	2.9
Parity/number of children		
1 – 3 children	6	17.2
4 – 6 children	16	45.7
7+	13	37.1
History of sexually transmitted diseases		
Yes	2	5.7
No	32	91.4
Do not know	1	2.9
Smoking habit		
Never smoked	35	100
Current		
Former smoker		
Alcohol		
Yes	4	11.4
No	21	60
Former	9	25.7

Table 4.4: The Stage at Diagnosis and Type of Cervical Cancer

Variable	**Frequency (n)**	**Percentage (%)**
Stage		
1B	2	5.7
1B2	2	5.7
2B	12	7
3B	14	40
4A	3	8.6
4B	2	5.7
Early (I & II)	16	45.7
Late (III & IV)	19	54.3
Type		
Adenocarcinoma	2	5.7
Spindle Cell Carcinoma	1	2.9
Squamous Cell Carcinoma	33	94.3

Research Question I

What are cervical cancer patient's perspectives on barriers to timely detection, treatment, and management of cervical cancer in Ghana?

Barriers to timely detection and diagnosis. Words like "early," "time," "took," had much dominance in this topic and were used to discuss barriers to the patient presenting for health care promptly. Early detection and diagnosis are critical in cervical cancer care. Early detection can prevent invasive cervical cancer from ever developing. Early diagnosis can inform prognosis, treatment, and management of the disease by way of treatment planning, service planning, and monitoring of progress throughout the continuum of care. This topic was broken into timely arrivals and delayed arrival, which tracks patients who sought medical assistance on time and delayed, which tracks patients that arrived late. Important reasons given for seeking early medical assistance were because the disease was unusual, and due to the severity of pain. The delayed hospital visit was attributed to a lack of knowledge about the disease and attitude towards the disease (most of them thought that the condition would go away).

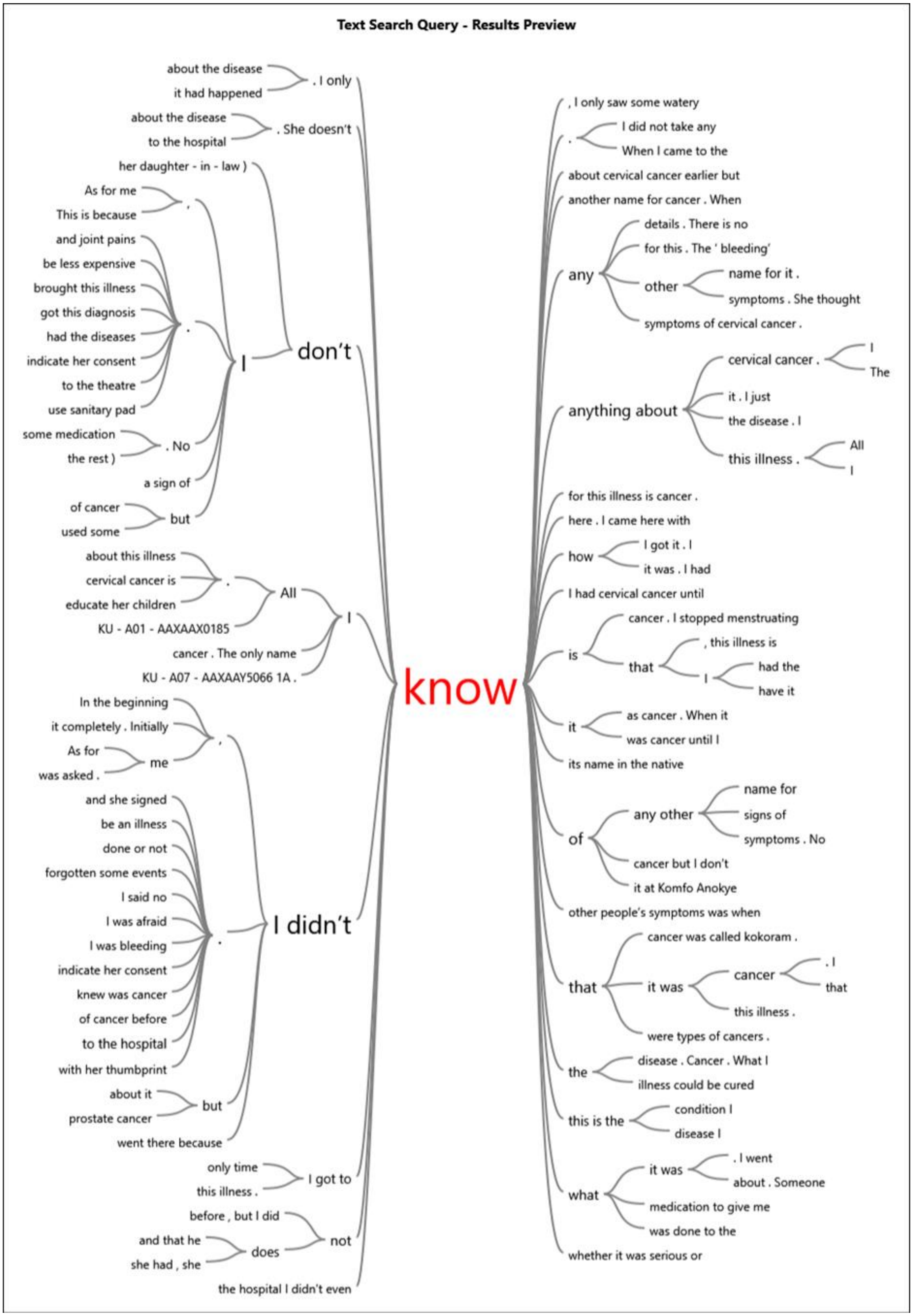
Cervical cancer patients cited several other barriers to timely detection, treatment, and management, as well, but the five overarching themes were (1) knowledge and attitude barriers, (2) cultural and religious belief barriers, (3) financial and structural barriers, (4) health system barriers, and (5) lack of community organization and government support barriers. These five themes encompass several sub-themes that will be discussed.

Theme 1: Knowledge and Attitude Barriers. A node was created for the responses to the topic area knowledge and attitudes. Word clouds were used to explore common words, while word trees were used to gain contexts to the usage of the words. Words such as "know," "heard," and "symptoms" had a significant appearance (Figure 4.1).

Figure 4.1: Example of Word Cloud for Knowledge and Attitudes

The word trees showed that the interview participant used them to express a lack of knowledge about cervical cancer (Figure 4.2).

Figure 4.2: Example of Word Tree for Knowledge and Attitudes



Sub-theme 1.1: Cervical cancer awareness (causes, signs, and symptoms). Most of the participants did not know about cervical cancer before their diagnosis. The few patients that had heard of cervical cancer it was from talks on TV from herbal medicine advertisement. Before diagnosis, most of them did not know the signs and symptoms associated with cervical cancer, and none of the patients was aware of the causes of cervical cancer. A few of the women were able to cite risk factors that they had learned about since being diagnosed. A lack of cervical cancer awareness was confirmed in some of their statements.

One patient stated:

> *"I didn't even know this disease; It was when I came here that I saw a lot of women here who had cervical cancer."*

Another patient stated:

> *"I don't know or haven't heard if anyone has had the same symptoms I had or cervical cancer before I was told that I have cervical cancer."*

Additionally, the patient stated:

> *"But where we live is a small village so until you are sick and you come to the hospital, and the doctor tells you that there's a certain disease called cancer that can really harm you so you should come for screening, either than that you won't even know."*

Sub-theme 1.2: Perceived susceptibility and seriousness. Other common words "serious" and "think" were also used to express the initial attitude about the disease. Most of the cervical cancer patients felt that the symptoms were possibly related to other female diseases (white) candidiasis, piles, or fibroids and initially did not think they had a serious condition such as cancer. Most only took their condition seriously when they began to experience dizziness, excessive bleeding, or pain.

One patient stated:

> *"It was one of my siblings that I used to tell, and with that, whenever I said it, my sibling will say that its white (candidiasis). That is why I did not send it to the hospital."*

Another patient stated:

> *"I didn't know that this disease is serious because I thought it was "white" all along."*

Other women thought that they just had bleeding in between periods, or it was due to sexual activity with a partner. Therefore, they did not initially take it as a serious illness until the symptoms continued. The woman thought that their symptoms would just go away.

One patient stated:

> *"I spent some time in the house thinking the sickness would go; I went to the hospital when I saw it was not going … My husband and I had no idea what the disease was about, so we did not treat it with urgency."*

Another patient stated:

> *"In my mind, this hadn't happened to me before, so I didn't think it was something scary or big when it happened initially. So, I was just checking up to see if it was getting worse. It's my daughter who took me to the hospital. "I didn't see it as any deadly disease because some people normally experience watery discharge but stop eventually."*

Sub-theme 1.3: Knowledge of cervical cancer screening. Most of the patients did not know about cervical cancer screening. "Screening" or "screened" is among the most used words to discuss the prior experience with cervical cancer screening and diagnosis. Knowledge was broken into two separate groups of individuals who had been previously screened and had experience with cervical cancer screening from those who had no experience. Most of the cases did not undergo screening before because they lacked basic awareness about cervical cancer or the need for screening. The one participant who had previously been screened was from the more urban areas of Ghana, and the screening occurred at a private hospital that she attended. Lack of knowledge of screening was prevalent, as shown in several cervical cancer patient-participants responses.

One patient stated:

> *"I have never had a screening for this illness before being diagnosed with it."*

Another patient stated:

> *"I didn't know anything about screening before I knew that I had this condition."*

Another patient stated:

> *"Before the condition, I hadn't screened for it before, and neither have I heard about screening for cervical cancer."*

Theme 2: Cultural and Religious Belief Barriers. Cultural and religious beliefs were seen to affect timely detection and diagnosis in the sense that patients often seek traditional medicine first when they become ill before presenting to the hospital. Cultural and religious beliefs also affect treatment and management when patients result in alternative medicine when they can't afford the treatment cost, or their symptoms don't seem to be getting better fast enough for them. African cultural beliefs gender norms, stigmatization of the disease and overall cultural shyness associated with the genital area prevents women from seeking care promptly and often prevents them from seeking preventive services and adhering to treatment and management plan for their illnesses

Sub-theme 2.1: Belief in alternative healing. Some women felt that the disease initially was potentially a punishment for something they did wrong or possibly someone performing witchcraft on them. This led the women to seek divine intervention and traditional medicine (herbal drugs) or prayer from pastors delaying them reporting to the hospital. This was confirmed by several patients' statements.

__Prayer:__

> *"My children told me they pray for me and that nothing would happen to me. With illnesses like this, you don't need to inform a lot of people because someone might be a witch or wizard, and they might change your mind about some stuff." (Patient statement)*
>
> *"The truth of the matter is that the time the doctor told me that I had this sickness, I was sad because I don't live a bad life and this sickness has come my way, so it disturbed me mentally. But I didn't know what I will do about it unless prayers to God asking Him to have mercy upon me." (Patient statement)*
>
> *"So when I got sick, and I didn't know what it was and I was losing weight constantly, my brother said that I should go for prayers, but I disagreed and said that if I go to the hospital and the doctor doesn't see or know what is wrong, then someone is doing me (witchcraft)." (Patient statement)*

__Herbal Medication:__

Patients often self-diagnose, and this resulted in the use of herbal medicines on their own or because of the suggestion of family, friends, or media. Several participants made statements similar to the ones below:

Patient statement:

> *"I woke up one day and noticed a whitish fluid discharge from my vagina. I thought it was "white," so I took herbal medicines for a while before I went to the hospital, and they gave me drugs to take."*

One patient stated:

> *"I used to hear about it on the radio, especially those who sell the herbal medications are those who spoke about it for me to hear of it."*

Another patient stated:

> *"There are some people who will have cervical cancer but because the local (or herbal drugs) are very common (they'll patronize them) because they are sick and want to get well by any means. They'll be all ready desperate."*

Additionally, another patient received advise:

> *"I told my grandmother about my symptoms. She told me to take some herbal medicine."*

Sub-theme 2.2: Fear of Stigmatization. Some common words included "siblings," "husband," "sister', "brother," "daughter," "told," "heard," anybody," "anyone," "children" were significantly used in this node. From the word trees, the context of usage is to discuss the people the cancer patient opened to, and if they heard people talk about their condition. It was useful to split the node int to two (those who opened up about their condition and those who did not. Those who opened about their condition were advised to go to the hospital. Conversely, those who chose not to disclose their condition cited "fear" of stigma or shyness as to the cause of not disclosing. Most of the participants said that they have not heard anybody in their communities talking about their condition They often fear being frowned upon or abandoned by family and friends if they are aware of the specifics of their disease.

Patient statements:

> *"Our society is not that friendly, in the sense that people want your downfall, so why then should I tell someone about my condition." (Patient statement)*

> *"I didn't tell anybody about my symptoms because this illness is shameful. If you go and tell someone, it is disgraceful. Before I was told that I had cancer, I used to say that my vaginal area is hurting." (Patient statement)*
>
> *"This illness is very disgraceful, so if the person has this illness, he or she won't tell you. They are shy." (Patient statement)*

Most felt that in African culture, it's not customary to share your illnesses with others, so it would be challenging to know if other women were experiencing similar symptoms.

One patient stated:

> *"I have not heard of anyone with the condition since I don't talk to people about it and nobody has also spoken to me about the condition before. It's only between I, my husband, and the doctor."*

Another reported:

> *"I stay in my house, so if someone else has had this condition, I would not hear of it."*

Additionally, a patient stated:

> *"I don't have a lot of friends, so I don't share my problems with anybody. Hence, I haven't heard anybody in my community talk about having the same symptoms I had."*

Sub-theme 2.3: Normative gender relations. Some women delay presenting for screening and diagnosis due to the location of the disease. According to their religious and cultural beliefs, it is inappropriate for their vaginal area to be examined while the husband is not present. Also, a few stated that there was a level of discomfort with the low number of female physicians available to perform the exams. In Ghanaian culture, the male typically supports the family financially, so he has authority over the decision as to when the female or children can seek medical care. Therefore, if the husband or male partner does not know about the disease, some women are unable to present to the hospital until given approval, which increases the delay in diagnosis and treatment. This was very prevalent in the participant's statements.

> *"People do not accept the screening because of their faith, and sometimes they are shy, why should you be shy since you'd be seen by the doctor while delivering a baby." (Patient statement)*
>
> *"What influenced me to accept the examination was because I was sick and because in our setting here, we don't have a place where females are examined by females only and males by males only." (Patient statement)*
>
> *"My husband, if he doesn't understand the cause of the condition, he's not really willing to help financially." (Patient statement)*
>
> *"I did not go to the hospital sooner because my husband asked me not to and also financial issues. I asked him to view my urine one day in order for him to understand what I was going through, but he still prevented me from going to the hospital." (Patient statement)*

Theme 3: Financial and Structural Barriers. Most of the patients experience a level of poverty that is characteristic of the country in which they live. Many of the women traveled far from their villages and communities to receive care at the tertiary hospital and felt that the financial burden would not be feasible for most women from their villages. Financial constraints are a major barrier to early detection, diagnosis, treatment, and management of cervical cancer. There is a significant cost associated with all aspects of the disease that presents major obstacles for patients and their families.

Sub-theme 3.1: Travel and accommodations. The availability of accommodation, too, was one of the critical issues regarding barriers to treatment and management of cervical cancer. Many respondents cited this in the interview section. Many patients responded that traveling from very long distances to access healthcare was a big challenge. A few patients cited that they slept outside throughout their care due to distance from their villages. This is evident in the examples showed below:

> *"You don't have any place here to sleep for treatment. It is a big problem when you come from a very far place to seek for medical treatment here. We sleep under the tree at the emergency block." (Patient statement)*
>
> *"I was referred to this hospital 11 months. I can't come here immediately the doctor gave me the referral letter, thus, in a week time but because of financial issues. I couldn't come." (Patient Statement)*

Sub-theme 3.2: Financial and social support system. Most patients said that their physical, material, financial, and moral support comes from family members' husbands, but they receive no support from government and community organizations. Fear of the financial burden it will have on their families also leads to delays, treatment, or continuation of treatment.

One patient stated:

> *"I didn't tell anybody; I was scared to tell mainly because of finance. I kept it to myself for about a year before I told my daughter-in-law about it, we don't have much, so we can find a loan to take care of me."*

Another patient stated:

> *"I get help from my children, nobody else. When I was told that I had cancer and asked to pay an amount of money, nobody helped me financially apart from my children. This illness requires a lot of funds, so when I said it, only my children helped me."*

Additional statement:

> *"My daughter and her husband have been looking after me. Before my husband was also helping, but he said he ran out of money, so I stopped getting help from him. He has two daughters; they have prevented him from giving me money."*

Sub-theme 3.3: Cost of diagnostic test and treatment. Participants also complained of the financial burden of the test (labs, CT scan, biopsy) that are required and drugs for treatment that are not covered under the NHIS or available in the hospital. This was considered a significant contributor to delay in seeking healthcare, adherence to treatment, and follow-up. Diagnostic facilities are not readily available in the peripheral communities, and the cost in more urban areas poses a barrier to timely detection and diagnosis. Almost all of the patients noted that the cost of the drugs and diagnostic tests was a major barrier, which is corroborated by several statements.

> *"I believe that this kind of cancer can be cured, but the controlling factor is money. So many people that I came here with have died because the medication is expensive." (Patient statement)*
>
> *"There are a lot of expenses associated with cervical cancer, so if the government can, it'd be helpful if they can subsidize the costs. Some people, when they learn of the expenses, they may not even return for treatment." (Patient statement)*
>
> *"The financial needs that need to be met because of this illness are a lot, so the government could come in. When I came here, maybe I can pay, but some people can't, so they tell them to go back home and get the money before they come. Should they go and die?" (Patient statement)*

Theme 4: Health Systems Barriers

Sub-theme 4.1: Limited access to health facilities and trained health professionals. The majority of the patients expressed that they were initially diagnosed with other illnesses either through selfdiagnosis or by health care professionals within their communities. Misdiagnosis poses a major barrier to the timely detection and diagnosis of cervical cancer, which significantly decreases the treatment options and successful management of the disease.

One patient stated:

> *"When it started, I was bleeding, and I reported it, and they told me it was fibroid. Every scan I went to take; I was told it was fibroid. When I took the scan, I was told the fibroid was not reducing. As such, they would have to remove my womb because of the way I was bleeding. If not, it will disturb me. As the operation was going on, I was still bleeding, and the doctor said he did not understand what was going on so he will check my vaginal area. When he did that, he saw that it was cancer, which wants to affect my womb."*

Another reported:

> *"I used to send it to the hospital at my hometown, and I was given medication, but it was not going, so the doctor advised me to send it to a bigger hospital since he did not know what was going on."*

Another patient stated:

> *"I went to the hospital near the post office because that is where I usually go to, and when you are ill, you advise to go to the hospital you usually go to. After going there for a month, I decided to visit another hospital because of my condition, and also some private doctors don't really have knowledge about conditions like this."*

Additionally, it was reported:

> *"This (delay) is because the first doctor I saw was not conversant with the condition and so had to transfer me to a different doctor who examined me and made me to have some tests."*

Sub-theme 4.2: Delays in the release of results. According to the hypothesized concept model, it was expected that the topic would cover patients' experience with the treatment process, information relayed to the patient, experience with the health workers, the timeframe to receive results, and overall management of the disease. Word frequency node showed that words like “took” and “results” were used significantly on the node, word trees of the words show that the context is to describe the time it took for the screening and diagnosis results to come back. A node was created with the passages which describe the length of time. Most of them said that the results were delayed; in most cases, they took up to a month. A couple of patients stated the results were delayed, and they had to pay for lab tests or specimen collection more than once because the specimen was lost, further delaying the results.

One patient stated:

> *“Samples were taken from her vagina, which was taken to Cape Coast for some tests. I don’t know if you know it. We did the first time when they took GHc300 or 400, and for about two months, the results weren’t coming. So, I went back to check up. I could see that after taking the money, they didn’t actually do the test. Later they made us do it again for another GHc300, so for that test, we spent about GHc700. They gave some excuses; something about the machines they use blah blah.”*

Additional statement:

“When I went there, I was made to do a biopsy test, which took two months to get the results.”

Sub-theme 4.3: Health information and provider interaction. “Helpful” was also significantly used to describe the experiences with the nurses and the health professionals. Most patients found the health workers supportive and useful. Also, doctors were used to describe the health professionals as the main person who told patients the results of the test or recommended the test. “told,” “illness,” “cause” was used to describe the information relayed to the patient, most patients were not told the causes of the illness and little information was relayed about their stage of cancer. Some of the patients did not seem to be aware of the treatment side effects before having the bad experiences.

One patient reported:

> *“One problem here is that when you’re sick, they just treat you. They won’t tell you much about what is bothering you. So, if you’re someone who doesn’t like asking questions, you’ll just go on with the treatment. They don’t explain the purpose(s) behind the things they do. They just tell you, and you comply. Here, it’s not a habit of them to explain things, for instance, the stage reached and so on. It’s not their habit. They just treat you. So, if you don’t ask, you’ll just comply. Sometimes you can’t ask so you’ll just do.”*

Another stated:

> *“Here, it’s not a habit of them to explain things, for instance, the stage reached and so on. It’s not their habit. They just treat you. So, if you don’t ask, you’ll just comply. Sometimes you can’t ask, so you’ll just do. They just take the result; that’s all. They won’t explain the results. It’s one major problem here.”*

Additional patient statements:

> *“No, they didn’t discuss options, he just said I would be put on a machine, but he discussed the consequences like you could be nauseous, you could vomit, and you could defecate on yourself.” (Patient statement)*

> *"They didn't explain; they only told me to go for a CT scan and bring it. The doctor didn't tell me anything about the stage; they only told me they would put me on the therapy machine." (Patient statement)*

Sub-theme 4.4: Equipment, equipment maintenance, and resources. "Sore," "machine," and "radiotherapy" direct the discussion on tests done, experience with the machines, and cancer treatment side effects. Generally, the sub-theme here is the experience with the treatment process. Patients often have bad experiences with the machine causing sores and pain. Also, the patients felt their health deteriorated more with the treatment process. Issues with equipment were confirmed by patients' statements.

Treatment equipment:

> *"Some people even die. Some people get diarrhea and vomit. Some people cannot even stand the treatment, so when they are done with that session, they go home and come no more or go to another hospital." (Patient statement)*
>
> *"I will be put on a machine, and that is what they did. When you are put on the machine, it is very painful because you get sores at you back, I could even vomit in the room, and sometimes you can lose your appetite." (Patient statement)*

Broken equipment:

> *"The doctors and the nurses took very good care of me, but the only problem we faced was that when they give you an appointment date for treatment, and you come, they tell you that the machine is faulty; meanwhile, the patient might be suffering." (Patient statement)*
>
> *"When it was time for treatment, I was told that the machine was spoilt. It took 40 days for the machine to be fixed and for me to be called." (Patient statement)*

> *"When it happened like that, they gave me an appointment date, and I came, they gave me 2months and 2weeks to come. When I came, they also scheduled me to three weeks' time, but when I came, they postponed me for some time, saying that the machine is faulty." (Patient statement)*

Sub-theme 4.5: Patient navigation. Patients also complain of delays due to inefficient appointment scheduling. The wait time on days that they receive treatment are often lengthy, and there is a perceived level of favoritism when it comes to what order patients are seen by the doctors.

One patient stated:

> *"When I came here for the first day for the tests, the appointment for the second time was too much. The first appointment was on the 25th of June and the second one was on the 9th of July. It takes too long, which can kill the person."*

Appointment scheduling:

> *"The timing and appointment dates here is very disturbing. Because I have gone somewhere to be screened and the doctor refers me here, and you are asked to come in 2 weeks to see a doctor at the oncology lab. Within the two weeks, anything can happen. Hence if this is the person's first time, help the person. Try to push the appointment date forward so that the person can see the doctor early and know the way forward. This is because if you tell the person to wait for two weeks before seeing the doctor, it is really disturbing. If the person wasn't feeling anything, they won't ask the person to come here." (Patient statement)*
>
> *"The day I came here, I was told that time was far spent so I should go and come back in a week. I came after a week, and they kept postponing it for about four weeks before they*

> *went to take a measurement of where the sickness is before I was put on the machine.” (Patient statement)*

Favoritism:

> *“However, at Komfo Anokye, the delay is too much. The nurses here say that we should form a queue, but it doesn’t go well at all. It is supposed to be a card by card method, but when you come, other people are served first. So, you come very early and queue, but you leave here late.” (Patient statement)*
>
> *“My husband works here, so I didn’t take a long time to be examined. The process did not take long, but I can’t state the time.” (Patient statement)*

Theme 5: Lack of Community Organization and Government Support Barriers

Sub-theme 5.1: Community or government-sponsored educational awareness. Participants noted minimal messaging, education, or other cancer awareness activities. Most individuals had not heard any government or community organizations discussing cervical cancer. Most women were not aware of any cervical cancer screening or education efforts in their communities. There were no policies or mandates that allowed for or promoted screening for the patients. Most had not been screened or heard of screening before their diagnosis.

Sub-theme 5.2: Inadequate insurance coverage. Most participants had insurance, but it was considered inadequate because all of the services were not covered. The lack of adequate insurance coverage and other supplemental health programs is a barrier for most women in Ghana due to the socio-economic status of the country. The patient was still responsible for many of the costs, such as diagnostic tests, labs, various treatments, and the purchase of medications when not available in the hospital facilities.

One patient stated:

> *"I don't see the insurance covering anything. Virtually everything we have to pay for, including drug."*

Another patient reported:

> *"In Ghana, we take insurance, but it does not cover most of the things with this illness, we have to pay for ourselves, so if the government can help with that, it will remove some burden from individuals. For instance, people who do not have the money to afford treatment goes back home and die."*

Additional patient statements:

> *"This Friday will be two weeks since I started this treatment plan. We were seven, but only two could afford it. Now that they have to go home, what will they do? However, when we came, they collected our insurance cards, but it is not covering anything." (Patient statement)*
>
> *"I had to buy the drugs for the chemotherapy myself because they didn't have some around, and it costed Gh₵ 200 at the drug store. The blood I had to take also costed Gh₵700, and I had to take 4 of that." (Patient statement)*

Research Question II

What are cervical cancer patients' perspectives on strategies to improve cervical cancer care in Ghana?

The overarching theme is a community and government support. Several sub-themes are discussed below. Discussion of strategies, words like "churches," "come," "educate," "women," "community," "market," "exercise," "advice," "treatment" are the most commonly used words. The context of use was to discuss societal support through community-based programs in place or needed. Also, the familiar places these programs are held or can be held. The discussion of the bodies /individuals involved or whose input is expected and most appropriate to deliver cervical cancer awareness messaging.

Strategies to Counter Barriers

Theme 1: Cervical Cancer Education

Most participants expressed a need for cervical cancer education in their villages. The woman in the villages need education so that they know to go to the hospital immediately if they have these symptoms. Locations suggested for education included churches, mosques, community centers, and hospitals in the villages. Most patients felt that health care professionals should provide the education because they are trusted and respected in the communities, and the women will listen. Also, due to stigmatization and misconceptions about the disease, it would be better received by the women from the health professionals.

One patient stated:

> *"Women should be told to go for check-ups periodically. If I had been going for check-ups, I could have prevented this disease from affecting me."*

Another patient stated:

> *"Where we live is a small village so until you are sick and you come to the hospital, and the doctor tells you that there's a certain disease called cervical cancer that can really harm you so you should come for screening, either than that you won't even know.*

Additional statements:

> *"The females in my community would be interested in a talk about the illness. You can go to the churches and schools because you can't really get everyone to talk, but on Sunday you have a lot of people going to church, and also you can get a lot of people in the*

> *schools too. I think it would help us a lot if you could take the initiative." (Patient statement)*
>
> *"The women in my community will be interested when you come around to educate them on cervical cancer. I think education and a screening exercise will help. All you need to do is make the Chief aware. He will make announcements and help mobilize the women for this exercise." (Patient statement)*

Theme 2: Health System Improvements

Most patients were not comfortable proposing changes to the health system in general. A few did note that improvement in the scheduling of services is needed; more explanation on causes and management of the disease, treatments, stage of cancer side effects, etc. would be helpful to the patients and families.

One patient stated:

> *"As for the queue, they have already explained to us that they attend to scarier and serious cases so those of us who only come for review normally keep long here, I suggest they should give us separate doctors for review and different doctors for treatments so as not to spend much time here."*

Another patient reported:

> *"I think what can be changed with the screening is that a woman should examine a woman because it's against my religion."*

Additionally, patient-reported:

> *"Well, what they can do is, when they treat you, they should explain what exactly the problem is, what stage it has got to, and so on. So that we can know what exactly is wrong with us. But to just get treated and go back without knowing what exactly is wrong*

> *with you and what stage it has got to. That’s the problem here. They have to tell something when they treat like the stage, whether it’s getting better, dos and don’ts. But to just get treated, when you go back home, you wouldn’t even know what to tell your family.”*

Theme 3: Community Outreach and Sensitization

Participants felt that the Ghana communities need to be informed that cervical cancer is not a contagious disease, and it is something that can be cured if you come to the hospital early. Community activities they propose are education on women's health about cervical cancer (by a health professional). The government and community organizations are asked to assist in providing services such as free screening and education sessions. Furthermore, it was suggested that screening exercises in schools and churches would be helpful. Most felt the topic was too technical to propose specific strategies for improving cervical cancer, but the majority felt education was needed and should take place in their communities.

> *“For people in my community, I think educating them on what causes, and the consequences of cervical cancer would sensitize most of them to go for the screening. This should take place at a community center. Yes, they would be interested because some people have come to perform eye screening and also breast examinations, and they attend them at the Methodist Church in our community.” (Patient statement)*
>
> *“We women we are very troublesome and ignore certain things so if we can move from one house to the other to inform them about a screening of the womb, breast, and that from your head to your feet anything can happen to you. Therefore, when you see any change in your body, you have to be able to go to the hospital for the doctor to check what is going on with you.” (Patient statement)*

Theme 4: Community Organization and Government Support for Cervical Cancer Care

The most used words in this node included “help,” “screening,” “church,” “government,” “money,” “treatment,” “doctors.” However, most patients felt a need for the government and community organizations to intervene on subsidies for diagnostic tests and treatment associated with cervical cancer car. If the insurance covers the testing and treatments, the participants felt that more women would seek out these services and present to the hospital early when signs and symptoms occur and remain compliant once treatment has begun. It was suggested that the government provide these services in the rural communities so that they are more accessible to women. Several patients reported similar statements confirming that government and community organization support is needed.

> *“I want the government to help us by subsidizing the cost for us. The disease is very expensive to cure. Some people come without a penny but is suffering. Would the person go back home and die or what?” (Patient statement)*
>
> *“The government should help us if you don’t have money you can’t treat this illness. If I’m to tell you the money I’ve spent on just the tests, it is not easy. Most of the women aren’t also working and so do not have money. So, the government should help us financially.” (Patient statement)*
>
> *“If the government could help us with the financial aspect, we would be very grateful. This is because the money I have spent here is not easy; it is nearly GhȻ 20,000.” (Patient statement)*
>
> *“What the government can do is a free screening, especially markets, churches, and so on where there are a lot of women so all women can go and do to find out whether they have*

> *cervical cancer or not. And if you don't have, you can be educated on how to prevent it. I feel if the government does this, it will help us, women." (Patient statement)*

Healthcare Professionals

The analysis process of the health professionals' interviews and focus groups was consistent with steps taken for cervical cancer patients' interviews. The first steps consisted of familiarization with the data reading and re-reading transcripts to note initial codes by the primary researcher and the secondary researcher. The second phase of the analysis involved both the primary and secondary researchers reviewing these initial codes. They considered the variation in the initial codes while developing higher-level components and overarching sub-themes. The research question and the SEM informed the process. In the third phase, the analysis conducted by the primary researcher and secondary researcher identified verbatim quotes that were consistent with the overarching themes. Next, both researchers reviewed themes before defining and naming them. Finally, once the themes were completed and agreed upon by both researchers, the report writing began to discuss the results of the participant group and the merged subthemes.

The health professional findings discussed in the context of the same five overarching themes as the cervical cancer patient's knowledge and attitudes barriers, (2) cultural and religious belief barriers, (3) financial and structural barriers, (4) health system barriers, and (5) lack of community organization and government support barriers. These five themes encompass several sub-themes. Additional details for merged themes and sub-themes are discussed in detail in chapter five.

Heath Professionals Background and Demographic Characteristics

The demographic characteristics of the health professional participants are displayed below in Table 4. The sample included a diverse set of health professionals (N=31) that see cervical cancer patients in various capacities (nurses, doctors, medical physicists, radiotherapists, gynecologists, and other support staff). There were 17 female participants and 14 males. The majority of the health professional respondents were between the age of 30 and 39 years, which represented 74.2% of the total participant population. Those between 20 and 29 years accounted for 12.9%. The rest of the categories had less than 10%. 74.2% of the participants were married, while 19.4% were single. There was one respondent who was separated, and another one was widowed. The majority of participants (96.8%) were Christians (n=30) and one responded traditional (n=1). There was a wide range of experience among the healthcare professionals from 1 year to 40 years, but the majority of the health professionals had 6-10 years (48.4%).

Table 4.5: Healthcare Professional Descriptive Statistics

Variable	**Frequency (n)**	**Percentage (%)**
Gender		
Female	17	54.8
Male	14	45.2
Age		
20-29	4	12.9
30-39	23	74.2
40-49	1	3.2
50-59	2	6.5
60+	1	3.2
Marital Status		
Single	6	19.4
Married	23	74.2
Separated	1	3.2
Widowed	1	3.2
Religion		
Christian	30	96.8
Traditional	1	3.2
Profession		
Doctor	5	16.1
Nurse	13	41.9
Social Services	4	12.9
Administrative	3	9.7
Other	6	19.4
Years in Healthcare		
1-5	6	19.4
6-10	15	48.4
11-15	7	22.5
>15	3	9.7

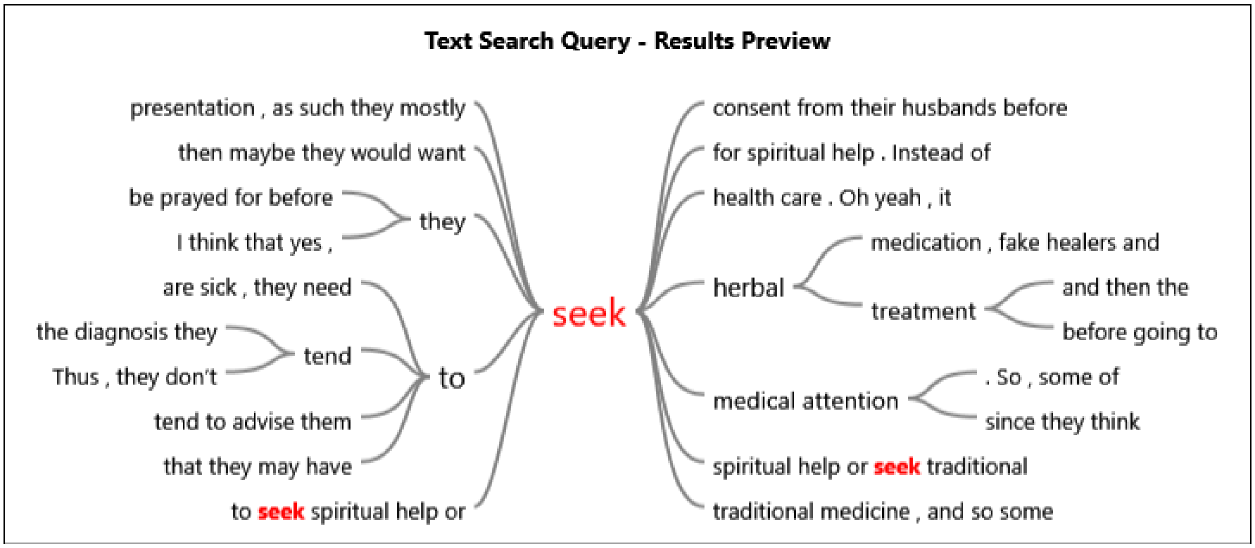
Research Question III

What are the healthcare professional's perspectives on barriers to timely detection, diagnosis, treatment, and management of cervical cancer in Ghana?

The general goal here is to discuss the barriers to timely detection and diagnosis of cervical cancer, prevention, treatment, and management of the disease from the perspective of health professionals. From a word cloud, some dominant relevant words were identified, which are related to the probes targeted under this topic. Some include support, challenge, cost, money, insurance, and others. A word tree of these words shows they were used to describe the difficulty of financial constraint. In other contexts, words like support, husbands, money, and others were used to describe influenced by family and level of family support, and the person who decides to go for screening. Culture, religion was used to describe cultural and religious barriers. Figure 4.3 shows an example of a word cloud and figure 4.4-word tree for theme cultural and religious beliefs.

Figure 4.3: Example of Word Cloud for Cultural and Religious Beliefs

Figure 4.4: Example of Word Tree for Cultural and Religious Beliefs



Theme 1: Knowledge and attitude barriers. Most health professionals believe that lack of knowledge about the disease and its symptoms leads to delay in seeking health assistance, similarly illiteracy level causes such delays. Most propose country-wide cancer awareness programs as a solution because there are varying levels of education needed around cervical cancer to improve the landscape of cervical cancer timely detection, treatment, and management outcomes.

Sub-theme 1.1: Patient and community awareness. The level of patient's knowledge about cervical cancer and its symptoms was founds to be a challenge to treatment and timely diagnosis. Most patients said that they knew nothing about the illness before being diagnosed. Also, illiteracy's lack of knowledge about cervical cancer in the community was discussed as hindering the spread of awareness. Most of the patients did not undergo screening before they were diagnosed with the illness. Most health professionals believe that a lack of knowledge about the disease and its symptoms leads to delay in seeking health assistance.

One health professional stated,

> *"I wouldn't think that people who are even around the hospital and for that matter those in the cities are more aware of cancer because people living in the city are preoccupied with their businesses and with awareness through radio programs, people in the peripheral listen better than those in the city"*

A health professional reported that,

> *I think the awareness is on the low side, majority of the population is semi-educated or illiterates, and they do not have any idea about the symptoms of cervical cancer and the need to go for regular screening, I think the main thing is the awareness and the second thing is probably the way in seeking treatment.*

Another health professional reported:

> *"...., there is a lack of or poor knowledge about the signs and symptoms of cancer in general. The awareness is not sufficient in the country."*

Sub-theme 1.2: Health provider knowledge. The educational background and experience of the health workers was captured on this node. Most health professionals admitted that they lacked specialized training and continued education in oncology at the tertiary hospital. Several health professionals also stated that the skills and training were more of a deficit at the peripheral hospitals and in the villages where patients are often seen several times and misdiagnosed before presenting to KATH.

A physician stated:

> *"As for the gap, a lot of doctors, nurses, all of them. Most of them haven't got the knowledge when it comes to certain types of diseases."*

A healthcare professional stated:

> *“In Ghana, community pharmacies haven’t got any knowledge when it comes to even common signs and symptoms of cancer. They have no knowledge. So, there was a big knowledge gap, even within the community pharmacist.”*

Sub-theme 1.3: Policymakers, stakeholder’s knowledge. Lack of leadership knowledge of cervical cancer and the burden of the disease on patients and their families is a barrier to the improvement of insurance and drug availability.

A doctor stated,

> *The policymakers sometimes don’t actually see the problems and challenges that you face. These are people that you see every day; you see, they can’t afford the treatment. The policymakers need to come down so they can see the real situations, so they can appreciate and understand what goes on. So that when you talk about reviving the health insurance, eventually all these things that are still cannot be given. Something can be done about it.*

Another health professional stated,

> *“For that, I know very well that for the management team, even government appointees they do have reps who are medical but I think, I am not so sure but either they get medical, people with medical fields on board so they can help in policy making because some of them might not be in the medical fields so they don’t really understand.”*

Theme 2: Financial Barriers. Financing the disease is a major challenge to timely diagnosis, treatment and management of the disease. Most of the cervical cancer patients in Ghana are experiencing extreme poverty. There is a known association between cervical cancer and low socio-economic status. After diagnosing the patients and developing treatment plans health professionals are often not able to begin treatment due to patient's inability to pay. Patients experience significant delays due to lack of finances.

A healthcare professional stated:

> *"Currently, I would say the main challenge is with financing the disease because unfortunately, we all know cervical cancer is a disease of low socio-economic status so most of our patients are very poor and the very few middle class well to do will not wait to get that advance before they come to the hospital."*

Another healthcare professional stated:

> *"Also realized that due to poverty people tend to go to alternative treatment instead of attending to hospitals or health facilities."*

Additionally, healthcare professional responded:

> *"One of the most stressful situations is when you diagnose a patient, and they cannot find money to undergo their treatment."*

Sub-theme 2.1: Travel and accommodations. Patients experience major financial issues because the tertiary facilities in Ghana that can treat cancer patients are located at the center of the country. There are only two such facilities and therefore patients have to travel very far to present to the hospital often without a place to stay or food to eat during the treatment process. This was evident in several of the health professionals' statements.

> *"So because of poverty most of them hardly even eat when they come for treatment and as they are taking a tray we realize that most of them that could be some of the reason why they come with low HB's and as some of the side effects of radiotherapy; weakness and the rest most of them are not even able to complete their treatment." (Healthcare professional statement)*

> *"Sometimes because they don't have money and they are sleeping at the outpatients; I think that even feeding is a problem. And you know nutrition is a very important aspect when you're treating a cancer patient. We really have challenges during the course of the treatment." (Healthcare professional statement)*
>
> *"where they would sleep when they come to the hospital especially the oncology unit that deals with the outpatients is a major challenge, most of the cases are outpatients, so they have to travel from their villages to this place and when they come, getting finance you know." (Healthcare professional statement)*
>
> *"To pay for their medical examinations also becomes more difficult, and after treatment, sometimes they have to come for us to see how best we can use our social support system to help them even go home." (Healthcare professional statement)*

Sub-theme 2.2: Financial and social support. Financial and social support was provided to patients mainly by family and friends. Husbands influence some women to get tested; others have unsupportive husbands who fear they cannot afford the cost, which delays presentation to the hospital for screening. The physical needs for cervical cancer patient, is limited, and the only source of financial support to these patients is family, most patients do not receive any social or financial support from the community organizations and limited support from the government by way of insurance. Also, culturally Ghanaian's believe that cancer is not curable, so the husband's and family members are less likely to want to pay for testing and support the women throughout treatment and management of the disease.

One health provider explained that:

> *"Most of our cervical cancer patients do not have any external support apart from their husbands and probably their children. In situations where they may not have husbands,*

> *or their husbands are not supportive, even attending the hospital becomes a major issue."*

Another health provider stated:

> *"Yeah, you would ask of marital status when you are taking particulars of patients, you would ask ad sometimes they would say 'I'm married but'. The moment you hear the 'but 'that means there is something somewhere and they would tell you their husbands are not responsible ever since the cancer started, they are not caring for them any longer, Financially."*

Sub-theme 2.3: Cost of diagnostic testing and treatment. According to health professionals, it is a barrier to seeking health assistance in time, facilitating screening, CT scans, transport, etc. Also, from the management perspective, the financial challenges pose issues because operational expenses are rarely met.

One health professional stated:

> *"Financial status, most of our patients are not able to afford their treatment so if even they come in, it will take them a month or two to gather funds to start and you know with tumor biology as you wait, things will be changing on its own so I think the main problem for our patients who finally get here and the diagnosis is made, they are not able to start their treatment because of funding."*

A health professional stated:

> *"Most of them have financial difficulties in affording most of the treatment procedures that they have to go through."*

Another health professional stated:

> *"Sometimes they have to go for a CT scan which they cannot afford so maybe they have to do with X-ray which may substitute, but actually, maybe the physician may need the CT, so these are some of the challenges."*

Another health professional:

> *"Barriers to seeking healthcare here is the financial aspect of the disease. Here most of the cases just like the chemo radiation patient may need about 16 cycles and each cycle is costing a little over 2,000GHC. Just had a patient last week that was supposed to pay $1008 GHC for 6 cycles. His understand, the thought that it would cover all the cycles. Not knowing that each cycle he has to pay 1008GHC. When I explained to him, he said I will just go home and die because he can't get the dose money to enjoy the cycles."*

Theme 3: Cultural and Religious Belief Barriers

Sub-theme 3.1: Belief in alternative healing. Cultural and religious beliefs affected appropriate health-seeking behavior in the sense that patients go to herbalists, and spiritual healers, during early signs and get to the hospital at extreme stages.

> *"We can catch them early, but they default and go and do all these things and come back. Yeah, we have patients like that they go to religious leaders either pastors or traditional people to go and continue treatment, people think it is a curse, they go and turn the curse and other stuffs, but they come back with the condition even worse."*
>
> *"in terms of, culturally, well across religions they normally have perception that cancer is demonic or devilish so they must inform their pastor about it."(Health professional statement)*

> *"Their religious belief. Some people have the notion that once you are diagnosed with the disease it's at the hand. Some believe that it is spiritual, so they prefer going to the other places for treatment instead of the hospital." (Health professional statement)*

One physician stated:

> *"What we realized was because of our cultural belief's and superstition people perceived cancer in a different way. So, the misconceptions cause most of the delay"*

Another physician stated:

> *"Patients feel diagnosis of cancer is spiritual, so they go see traditional healers and when they come back to the hospital the cancer has spread to stage III and IV."*

A nurse revealed that:

> *Pastors and traditional people have also taken a chunk of our patients treating them but some to no avail. They come back to us. Hmmm, spiritualist, and our traditional herbal attendance. They spend a long time there, and by the time they get here, there is nothing we can do.*

Sub-theme 3.2: Normative and gender relations. Most health professionals stated that women are dependent on their husbands, so the decision to get tested is from a third party. Also, religion, some women believe that only their partners should see/touch their private parts and are less willing to seek out the examination**.**

A physician also reported that:

> *"A few from the north … some of them their religion requires that their husbands have to follow them to the hospital every time, the husband must be present when you are doing the vagina examination and all that, so if the husband does not show up, that means the*

> *patient is not going to show up because the husband has to be with her or a male member of the family has to be with her"*

A nurse reported that:

> *"Either your partner, your husband, so everything will boil down to when the person footing your bill is ready. So that's been a challenge knowing that most of them come from low resource places. Kind of, the empowerment to even seek healthcare will depend on your spouse."*

Another physician stated:

> *They lack knowledge of cervical cancers or cancers in general. And then cultural practices, some people think that especially women, when they are sick, they need to seek consent from their husbands before going to the hospital.*

Sub-theme 3.3: Fear and stigmatization

A nurse stated:

> *"In the community you know there is a stigma attached to cancer and unfortunately where we are its still prevalent because we get patient's relative coming to ask and asking "is it infectious?" so some people when they are in the community they don't even want other people to know they have cancer, u get it?"*

Healthcare professional stated:

> *"I know about some women the husband left them… because they have cancer. And some of them too because they don't want to be stigmatized. Most of them even come here, you see somebody… they cover their head… he doesn't want the person to see. Stigmatization in the community, so he wouldn't even come out."*

Another healthcare professional stated:

> *"Well in our community, when we see that a patient is a cancer patient, you see the stigmatization and such things like that. "we make sure that we keep their documents confidential, and that's what we do here."*

Additional statement by doctor:

> *"Because in issues where when patients are diagnosed with cervical cancer, I mean they are divorced and for that reason even for patients coming here, we have quite a number of them, maybe not up to 50% who do not want their husbands to see that they have been diagnosed with cervical cancer because of the stigma that they are associated with cancer disease."*

Theme 4: Health System Barriers

A word frequency was used to discover dominant words related to the probes under this node., some common words include equipment, knowledge, treatment, screening delay hospital, etc. the context of use was to describe, the experience and issues within the healthcare system.

Sub-theme 4.1: Limited access to health facilities and trained health professionals. There are not enough health facilities to carry out screening, diagnosis, and treatment in the rural areas of Ghana. Patients, therefore, have to travel far. The tertiary facilities do not offer housing for cervical cancer treatment which is a big challenge. Also, government cancer centers are limited, and the private hospitals and cancer centers are much more expensive. There is a need for more trained specialists to handle the cases. Also, most health professionals in Ghana who are treating cervical cancer patients are not experienced or trained in the field of oncology. This leads to high levels of misdiagnosed patients being prescribed inaccurate treatment for their conditions, resulting in delays.

A doctor reported that:

> *“We don’t have enough specialists. For now, in Ghana, I can only say we have one gynecology oncologist. The whole northern sector is only Kumasi, where we provide gynecologic cancer services.”*

Additional healthcare professional statements:

> *” Most of the peripheral hospitals don’t have facilities for biopsy. And when I say that I mean they don’t have pathological services so they may have the expertise to do the biopsy, so when they do it over there, then they have to send it to the cities, some of the big towns to get the diagnosis, go back to doctor before the doctor refers.”(Healthcare professional)*
>
> *“Another problem is the facilities we treat the cervical cancer patients we only have two in the region now. In Ghana here one private and two government hospitals that we treat cervical cancer. In Kumasi, it located in the middle of the country, people are coming from the North, people from the eastern region, people from the western region, and the bottom half region.” (Healthcare professional)*
>
> *“There are limited screening centers I will say. Also, people do not have access to the health facilities. You don’t have many health centers not even CHIP compounds in this country let alone regional hospitals. There is less accessibility to our health facilities.” (Healthcare professional)*

Sub-theme 4.2: Equipment, equipment maintenance and resources. According to the health care professionals' lack of enough treatment, equipment pap test kits, and resources such as personnel, pathology services are critical barriers to early detection and diagnosis of cervical cancer. This poses a significant challenge for the detection, diagnosis, treatment, and management of cervical cancer. Also, there are several services and medications that the patients need that are not covered under the Ghana National Health Insurance Scheme (NHIS). State of the art equipment is limited in Ghana and often is outdated and does not perform correctly. The time it takes for repairs often delays the treatment process for patients and contributes to loss to follow-up. There is also a significant deficit in the Ghanaian healthcare workforce. There is a shortage of experienced oncology specialists and pathology services. This was stated as a barrier to screening, diagnosis, and the treatment process.

A physician stated:

> *"I mean regular breakdown of the machine; government doesn't cough out the money as soon as possible and it affects the treatment because I mean cervical cancer from the medical point of view is a very rapid growing malignancy. So, if I start treatment from the protocols and the trials that you want to complete treatment by five or six weeks else there's going to be a repopulation of the cancer cells and then we have breakdowns, and the disease starts repopulating."*

A healthcare professional stated:

> *"Equipment maintenance is a problem as well as proper training on how to use some of the equipment."*

> *"When it comes to drugs the same thing, the drugs that are needed for the patients are not there; if they are there, it's costly." (Healthcare professional)*

> *"For the screening aspect it is not that widespread. Currently few facilities are doing the visual inspection, others are doing pap smear and few people are even doing HPV. It takes people with knowledge about screening aspect or modalities or to know that facilities are*

> *doing this. It's not available or that people are aware there is a screening point here that I should go and do screening" (Healthcare professional)*
>
> *"to the facility sometimes its due to the shortage of kits to do pap smear." (Healthcare professional)*

Sub-theme 4.3: Challenges in referral process and follow-ups. Critical information such as the histology reports are missing. When following up with referring facilities, the patient's reports typically have not been completed. Also, cases that should be handled at the district-level hospitals are referred to KATH, which creates congestion at the referral level. The follow-up process becomes challenging to navigate when the patient has financial problems. In most cases, it is the external referral that led to a high number of patients lost in the referral process. The internal process within KATH has its issues but is more streamlined than the external process. A physician reported that:

> *The main challenge is that the patient comes in delay, so most of the patients we get are delayed either from the patient's own doing or from the referral doctors. Some doctors would keep the patients for some time before referring the patient, and by the time the patient gets here, the patient has already delayed, and there's little we can do, and then some patients also delay in seeking health, so because of that they also delay in coming here.*

A health professional also reported that:

> *… when they bring it, the referral must come with a histopathology report, and the histopathology report declares the case cancerous, but sometimes they come without the histopathology report, and when you make a follow-up, they are yet working on the histopathology report.*

Additionally, several healthcare professionals reported:

> *"Generally, you have the belief that if these patients had been diagnosed on time at the periphery, they'd have probably come to us on time. But you listen to the history closely, and you find out they have been seen by the peripheral hospital and being treated maybe for a vaginal discharge or bleeding with maybe one, vaginal suppository after the other and there are times that you realize a patient might have visited an institution with vaginal discharge or bleeding, given treatment, being followed up for about 3 months and no pelvic examination has been done. Until such a time that maybe the patient's condition is not improving, and then either patient opts to see another doctor or maybe one day the doctor does the examination for which the diagnosis will be made, and then he will be referred here."(Healthcare professional statement)*
>
> *"There is no communication within these hospitals and even these clinics just in this region. How are they supposed to communicate? There is no standard for them. Over here is the ministry of health, but when you talk about the other clinics, they are under the Ghana Health Service. We are not under the Ghana Health Service, we are under the ministry, because we are a teaching hospital."." (Healthcare professional statement)*
>
> *"Within the Ghana Health Service, they have their own protocols, they have their own referral letters, so they have what the referral letter is supposed to contain, what you are supposed to bring. When you get to the teaching hospital you also have a different protocol. You realize that there is a gap, there is no synchronization among them, in respect to, whether you are under the ministry or whether you are under the health service. Averagely, or let me say minimal three months. Some of them might never come back. The system is frustrating." ."(Healthcare professional statement)*

> *"The problem here, you can say in Kumasi or Africa in general is the referral system. Because it takes time before the patient gets to the center. Before the patient gets to this place, the patient might have walked through so many facilities before he was referred to this center for the treatment.".'' (Healthcare professional statement)*

Sub-theme 4.4: Lack of psychosocial support. Emotional support in terms of encouragement was also pointed out as a need for cervical cancer patients. This poses a significant treatment barrier for patient stability throughout the treatment process. Some women are abandoned by family and their husbands when they go to the hospital for cervical cancer.

A nurse stated:

> *"As for the counselling part, we do our very best because then patients normally listen to other patients their experiences so we try to debunk their minds from the reason why they should go through the process."*

A physician reported:

> *"Our health system pays very minimal time to mental health but that said, our nurses double up as that, I mean personally I think there's a lot of work for the doctors. We are not many, the patients are a lot, but we have a lot of nurses now, so we pull out a couple of them.*

A doctor stated:

> *"Most of them, maybe, especially the married ladies. Most of them, the husbands abandon them. So, they come, and they say, "my husband left me because of cancer I don't have money to continue the treatment."*
>
> *"Most of our cervical cancer patients do not have any external support apart from their husbands and probably their children. In situations where they may not have husbands,*

> *or their husbands are not supportive, even attending the hospital becomes a major issue." (Healthcare professional)*
>
> *"Now some of the women, for one reason or the other will also delay because probably they don't want their husbands or spouses to see that they have cervical cancer and they will conceal whatever is going on from their husbands and, until such a time that probably the discharge will become so offensive or maybe the vagina mass is such that maybe during coitus the husband will realize something is not right." (Healthcare professional)*
>
> *"Also, most women feel shy informing their husbands about the symptoms especially with the vaginal bleeding and discharge. They then tend to hide it from them. As such, support mostly comes from other family members other than their husbands. This is also due to our setting here where the man has to work to support the family and as such have less time to visit the hospital with their spouses." (Healthcare professional)*

Sub-theme 4.5: Palliative care policies and palliative care teams. Experience with treatment and pain management discussion was centered around the physical suffering of cervical cancer patients, whether that be from the disease itself, procedures, or cancer treatment side effects. Availability of drugs, palliative care team, and facilities to manage pain were insufficient.

> *"Sometimes they feel they came with pain, you gave them palliative care, the have the pain relieved, pain is gone, no enough money, they don't come again. Others will do part of the treatment and looking at maybe the complications they had from chemo, they declare themselves fit. They don't return. So, we actually lose some to follow up." (Healthcare professional)*

> *“It’s a problem when it comes to pain; pain is not diagnosed in this hospital. When you go through these old hospital folders, you realize that there are these certain things that we always check for. They will do the Bp and certain vital signs. Nobody asks about pain; they didn’t diagnose the pain… they just wait for the patient to say I am having this pain; we don’t actually assess the pain to see what level. And when we provide the medication, we don’t know whether the medications, maybe the patient is getting the relief or not.” (Healthcare professional)*
>
> *“Initially, we had morphine. We still have it; it was very cheap and covered under the insurance… it was very easy for patients to access the morphine. We still have access; now it’s not in the insurance, they have to pay for it.” (Healthcare professional)*
>
> *“When they come in and you let them know that oh its palliative and family members do not see any improvement even though you explained to them that its palliative, having them follow up come like come two months or three months and it doesn’t work they won’t come because they feel that I mean it’s not worth spending money knowing that the doctor said he’s not gone live. So, with palliative care that’s our major challenge, people are yet to understand” (Healthcare professional)*

Sub-theme 4.6: Patient navigation and provider interaction. According to health professionals, the conduct of health workers, is also a challenge to the patients, which entails poor management of the queuing system. Favoritism is shown to patients that the workers are familiar with when it comes to who is being seen by the doctors on specific days. Also, it was noted that some patients come to the facilities and do not know where to go or appointments are rescheduled for two weeks out, and they do not return. Some patients only nod when the physician provides information and instructions. The patients wait until they are with the nursing staff to ask questions that they did not want to ask the doctor or clarification on things they did not understand. Some patients remain quiet.

One health professional stated:

> *Yeah, because when you talk about where people seek care, the easiest place for them to go is the community pharmacy, the traditionalist, the herbalist, before they come to the hospital. The hospital is a very scary place for them. Somewhere that they can feel a connection between them as people, I've been to an herbalist before, whereby I just wanted to see how things are being practiced there. You realized there is a queue of people that are going to see them. The way a traditionalist walks back and forth and says, "I'll be with you soon, are you okay?" "What happened this morning; how were you able to get here" the kind of interaction, there is a kind of connection between them and the people who are waiting on them.*

Another health professional stated:

> *They come to the hospital you are being shouted at, as you are talking the nurse, or the doctor is writing. Even to maybe to examine you. I know you are supposed to wear gloves, but sometimes you are supposed to show some kind of connection. If you have to feel a lump in the neck, I don't think you have to use gloves. You can use your bare hands and wash it. Over here, we are kind of small gods, but when you go to the traditionalist, the kind of communication, the connection. There is no way that this patient will come here. I mean, everybody wants to be treated when they are sick.*

Another health professional stated:

> *People are afraid to come to the hospital because of the navigation system. They see doctors as some kind of mini gods that you can go to them, but you are very much afraid*

> *to express yourself. Express how you are feeling and stuff like that. And because the health care system is very complex, if you know somebody, you navigate your way in and out very easily. If you don't know anybody, it is quite very difficult. Getting information as to where to move from A to B, from B to C, is quite difficult. There is no information service within the hospital that patients can even ask, "well I am coming to the hospital, where do I start from?" where do I end and stuff like that, so the navigation is a very big challenge.*

Theme 5: Community Organization and Government Barriers

Probes on this node were to better understand the need for community organizations, government policies, and support groups. Words like support, government, insurance, money, education, groups were used to describe the existing policies, recommended policies and community organization partnerships needed.

*Sub-theme 5.1: Community organization and government support***.** Existing community groups and mentioned included the ministry of health representatives and their administrators. Non-governmental organizations offering material support, screening, and awareness services were noted. NHIS and pharmaceutical companies that run campaigns against cervical cancer have existed in the past. None of the efforts were noted as being adequate to address the need for community and government organization support that exist within this area.

A healthcare professional reported:

> *"Well in our culture you see I even started with a group of that sort, but it couldn't survive people do not want to expose their illness in our part of the world especially Ghanian because of cultural beliefs Because of mistrust people don't want to disclose their illness to other people and they know that this women is suffering from this disease they think people feel it may spread. People feel reluctant to join such groups especially the cervical*

> *cancer. Even some even feel reluctant to expose even to their own husbands. So that is a big challenge."*

Sub-theme 5.2: Reimbursement for insurance claims. The hospital faces major challenges with repair of equipment, purchase of equipment and stock piling of treatments when reimbursement is delayed. This causes a financial strain on the health facilities that leads to inability to properly treat and manage cervical cancer patients.

One health professional stated:

> *One of the most stressful situations is when you diagnose a patient, and they cannot find money to undergo their treatment. As we speak now, the radiotherapy equipment is always there, that's fine, but then when you have to; I mean they have relapsed kind of, and they've progressed, and you want to introduce chemotherapy, and you don't have the agents it means you have to buy them. Because the hospital has not been able to stock. The hospital has not been able to stock because the insurance is not reimbursing them. So, it's a vicious cycle. At the end of the day, it is the patient who suffers because they don't have the money to buy the medication. And that means you can't do anything.*

Sub-theme 5.3: Inadequate insurance. Although most patients in Ghana have the National Insurance the coverage is considered inadequate for cervical cancer. Also, there are no mandated policies in place at the institutional level or the national level for cervical cancer screening.

<u>Coverage:</u>

A physician stated:

> *"The insurance won't work because our insurance is burdened. They would rather want to spend a lot of money on malaria, a lot of money on diarrhea and kits, a lot of money on pneumonia and kits because they feel ok that's more rewarding, that would cover a lot of*

> *people but if they are going to disperse may be 20000$, it going to cover just one hundred or two hundred patients."*

Another healthcare professional stated:

> *"The government should make sure that the health insurances fully* cover breast and *cervical cancer and treatment. Because of the poverty. Poverty is one of the barriers."*

Additionally, healthcare professional reported:

> *"Screening and the HPV vaccine should be free, and the vaccine should be stockpiled."*

Another healthcare professional proposed:

> *"There has to be, we need a kind of institutional protocols. We don't have national protocols for screening or institutional protocols for screening."*

Research Question IV

What are health professionals' perspectives on strategies to improve cervical cancer care in Ghana?

Strategies to Counter Barriers

The probes in the last section are about strategies useful in improving cervical cancer care. Words like support, finance, community, education, vaccine, know, government, strategies, etc. are used in the context of describing the actionable plan to counter the illness. Several strategies to improve cervical cancer care were summarized and listed below. Direct quotes from participants are included to support themes.

Theme 1: Cervical Cancer Education and sexual health education in schools, churches, community centers

One physician stated:

> *"So at the patient level I think that education of cervical cancer, the community levels and then healthcare providers at the district level, yes they also need to be educated and empowered on the need to suspect, I mean have in them suspicion for cancers especially cervical and breast cancers."*

Another healthcare professional stated:

> *"I think that education should also target youth. The second and third cycle institutions, when they are not out of school, they take the chance to screen them. That is one very effective way of going about it."*

Additionally, healthcare professional reported:

> *"So, we also avail ourselves as an institution when these colleges or universities are having their annual celebrations, and they want to have a talk show, we readily avail ourselves for such thing because if you educate them, they take the message out there and the education goes around.*

Theme 2: Community Outreach and Sensitization

Enhance public education and awareness (open and in media)

Healthcare professional stated:

> *"Sometimes it is about education… the knowledge is very minimal. The noise we make about cervical cancer is less. less than breast cancer." (Healthcare professional statement)*
>
> *"We also need the support of the media. The airways can go and cover a larger area. If they are able to support us, we go on air and educate the mass. Think that was all we need the support from the media." (Healthcare professional statement)*

Use of social media platforms and artist to promote cancer awareness

One physician proposed:

> *"So, if you have some kind of public education. Social media is very powerful not, public education throughs social medias in local dialects. That will be very powerful tool. but something that I have talked about, and something that I am working on. Is to be able to get leaflets even on certain types of cancers, is different dialects. That people can read, also pictorial forms that people can look at an understand basic signs and symptoms."*

Fighting stigma in cancer patients

One physician stated:

> *I think we also need to use icons and personalities when it comes to awareness creation. These artists can move the youth, so when they are championing the course of something, everybody wants to know what is this guy doing? These are some of the strategies that I think we can use.*

Inclusion of men and cervical cancer patients in intervention development

Another physician stated:

> *And I don't think we should leave that for women; the men must also be involved. It will be easy to involve the men to get their wives to screen because eventually if they are diagnosed, and nobody is paying for them, they have to pay for them. So, we don't leave the responsibility to the women, and I think we should involve the men.*

Additional statement captured by healthcare professional:

> *"For me I for instances wherever I go I try to involve the men. Most of the men they shun their wives when they see that they are in that conditions whether cervical cancer or breast cancer. So, wherever I go especially in the churches or the mosque I try to involve*

> *the men in my education. Men should be involved so you can explain things to them and win their support from them for their wives."*

Community leaders, policymakers and other stakeholder education on cervical cancer

> *"non-governmental organization can help generate fund for patient and also help in education. I think education is very important because sometimes from the start of the problem, the person wouldn't know it could emanate to that, but the person been aware and been cautious I think prevention is better than cure, so education is really important." (Healthcare professional statement)*

Partnerships with the village and other community leaders to promote cancer awareness

One physician stated as a strategy:

> *"Health care providers people respect them when they are health care providers in our part of the world. So, when they approach the stakeholders the chiefs all those people and the queen mother and tell them their mission they will cooperate. So, they can use the stakeholders, or the gate keeper's assembly men, queen mother's, communities, executive members in the towns or the villages and then the chiefs they can use them."*

Another proposed:

> *"In the village because of the mode of their hierarchy, something is coming from the Queen Mother that she wants to meet all the women in the village, on that day nobody might even go to the farm. So, it's very easy to mobilize them when it comes to this awareness creation."*

Another healthcare professional proposed:

> *"So, the cities it's through the organized groups at the headquarters, if you want to get the headquarters, you get their leader, they can put them together. But to say I want all*

> *the women in this suburb, that will be very difficult. So, the hairdresser's association, you can get them through their hair. Those units you can get but, in the village, you can get everybody because of their reverence for the Queen Mother and King and stuff like that. And the village committees."*

Theme 3: Health System Improvements

Formal communication plan to improve the referral process and patient navigation

> *"because the patient thinks oh I was referred from this village and I know So if we have a hotline that maybe that doctor who's referring calls and say oh I think I'm sending you a cervical cancer patient, I tell you just do your CT scan, do your ultrasound, do your chest X-ray before you come here so that when they come, we can start treatment immediately." (Healthcare professional statement)*
>
> *"I think with the referral connection, there has to be a kind of policy. That has to do with this referral system, whereby all these organizations come together and say okay I am in the teaching hospital and these are the things I need when it comes to the referrals, of maybe cancer patients, or maybe generally. These are the things that we require, basically policy." (Healthcare professional statement)*

Partnership with alternative medicine providers, spiritual healer and community pharmacist to detect signs and symptoms of cervical cancer patients and refer early

> *"If even (the herbalist and traditional healers) have a referral form, that at the end of the day I've developed this referral form. All traditionalist and all herbalist, you just write our name and he feel as if he is being recognized taking cares of these patients. It's all about recognition; if somebody is providing something and is not being recognized it quite very difficult. If somebody is being recognized immediately he sees one, two,*

> *symptoms and I'm not really sure, let me give you this referral to the teaching hospital at the end of the day, patients are getting there early, getting treated, and feeling very proud. At the end of the day I am also somebody that can refer to the hospital, the hospital can call me back to discuss issues and stuff like that. But if we try to segregate ourselves from these people that is where the problem is." (Healthcare professional statement)*

Psychosocial support for cervical cancer patients and family members

> *"I think that the hospital should have a palliative care team and then also a support group system for the patients. There should be a patient support group where they would get support from each other and they would talk about their stories, comfort each and every one. (Healthcare professional statement)*

Workforce development in the community hospitals and tertiary facilities

> *"we need to train more personnel who will be readily available to take care of patients with cervical cancer, and we need to improve on our education. If we need to develop on our educational resources, whether videos or graphics which will talk about cervical cancer." (Healthcare professional statement)*
>
> *"I think the ministry of health the government should train more health care providers for that matter, even nurses and midwives, so they will be able to train them in cervical cancer screening so they will be able to help in the hinterlands." (Healthcare professional statement)*
>
> *"For the smaller hospitals they might not have specialists, maybe there maybe just house officers or physician assistant that manage the place, so I think maybe quarterly we from the teaching hospitals or the bigger hospitals can go to the smaller hospitals in the rural*

> *areas to have workshop, organize workshop and seminars for these physician assistants and nurses who are in charge there so that at least they can quickly do the referrals if they are not so sure of what to do." (Healthcare professional statement)*

State of the art cancer treatment equipment and maintenance

A healthcare professional stated:

> *"I would say our maintenance culture it should be something that is on top because the problem is got to do with the maintenance culture. Sometimes even with the external beam you will hear that, the radiotherapist will tell you the machine is faulty or this thing is faulty and it can take a while before patients are even treated and all these things are coming in to play to delay patient's treatment and I think if there is more improvement in these sides, it will go a long way to help the patients."*

Another healthcare professional reported:

> *"Maybe if equipment, maybe donated or someway of human resource training especially too because sometimes we get fatigue. Sometimes we wish that some other people would know how to do this so that we can lase better with the gyn-oncology that oh you see to our brachytherapy whiles we see to external beams, like some collaboration… we do have a collaboration with them, notwithstanding we do but we need help in terms of human resource training, in terms of equipment to manage cervical cancer."*

Access and availability of diagnostic services

Hospital-based interventions for palliative care inclusive of the palliative care team

> *"I think that the hospital should have a palliative care team and then also a support group system for the patients. There should be a patient support group where they would*

> *get support from each other and they would talk about their stories, comfort each and every one." (Healthcare professional statement)*

Theme 4: Community Organization and Government Support for Cervical Cancer Care

Expansion of NHIS to cover routine screening, vaccination, and 100% of cervical cancer treatment

A healthcare professional stated:

> *"The national insurance should cover cervical cancer and breast cancer fully. People will feel free to report to our health facilities. They want to keep running and running. Once they know anything like that it is free, they will report they will come. So, I will advocate for that."*

Another healthcare professional stated:

> *"We also need to look at how to secure adequate funding whether from local or international partners so that we can adequately treat patients with cervical cancer."*

Improve hospital reimbursement timeliness

> *"I would say getting money back from the insurance for services we have provided. We do everything right. Sometimes it takes some time for us to be reimbursed. The delay causes delay in treatment of patients when we need equipment." (Healthcare professional statement)*

Increase government and advocacy partnership support for cancer patients

> *" I think that there should be a foundation for patients with cervical cancer so that the cost aspect can be financed." (Healthcare professional statement)*

> *"I think we must also encourage the establishment of support groups in terms of support, like giving hope to the sick and support in terms of finance. All those things will help." (Healthcare professional statement)*
>
> *"Doing a lot of outreach to create awareness so that they can bring to the facilities with early detection so it can be managed. Last year we had a program at Kumasi mall cancer awareness month. That was in October. It was breast cancer awareness, but we took the opportunity to teach about cervical cancer." (Healthcare professional statement)*
>
> *"We need support from government, individuals, companies and philanthropist to help us so we can intensify the awareness. So, you can also reach out to the rural areas. Most of our people reside in the rural areas. They are the ones that are lacking the education. If you are well educated, they need more education because of the cultural beliefs and superstition to be able to understand why they need screening so you can prevent and detect it early." (Healthcare professional statement)*

Increase funding for hospital drug stockpile

A physician reported:

> *"National Health Insurance it is supposed to cover them for all of cervical cancer treatment but if the patient is on chemo and the drug is not in stock at the hospital pharmacy the patient has to pay* "

Regulation on public information about cervical cancer by the Food and Drug Administration

One physician stated:

> *I think one of the key things that need to be taken in developing the strategy is to do with information that is put in the public domain. Because that often is deceptive, that when people hear them, they believe them. For Ghana, I think the Food and Drugs Board*

> *should be up and doing. You cannot put any information in the public domain. All such information should be censored, especially information concerning cancer and the claim that they can be cured. I think we must also encourage the establishment of support groups in terms of support, like giving hope to the sick and support in terms of finance. All those things will help.*

Government-sponsored programs to provide community education and vaccine availability at low or no cost

Universal screening and tracking through National Identification System (NIS)

A physician stated:

> *For now, I think that the government could come out with a policy, a policy that should screen women or that oblige women to have themselves screened. Now that they're making the national ID, you could see all the women that fall into a certain category, a certain age, and then you can have them screened. Call them to come 3 to 5 years of screening. Besides that, create awareness, let them have voluntary screening, but then if there is a national program. The difficulty has been; who and who should get screened? How do you know them? But with the national ID, which is currently ongoing, I think it will be easy to mobilize and get women even if it's compulsory, so be it.*

CHAPTER 5

DISCUSSION, RECOMMENDATIONS, AND CONCLUSIONS

Discussion

Overall, cervical cancer patients and health professionals' perspectives on barriers to cervical cancer, timely detection, treatment, and management can be informed by the SEM levels. There are several themes and sub-themes at each level of the model. A multi-faceted approach is necessary to develop strategies to improve cervical cancer care that encompasses all these components. Therefore, a significant component of the discussion includes proposed strategies to overcome the barriers identified by the participants at each level of the SEM.

Knowledge of cervical cancer, financial barriers and other personal issues were most often addressed at the individual level and interpersonal level while social support, health system barriers, and adequacy of health services were addressed at the, community, organizational, and societal levels. The societal level includes policies that provide laws and regulations that influence the availability of cervical cancer awareness education, prevention programs, health services, and community support often offered through the community level and organizational levels to the individual. Lack of knowledge of cervical cancer and financial constraints was addressed in some capacity at all levels of the SEM.

Barriers to timely detection, treatment, and management

The barriers to timely detection, treatment, and management at each level of the SEM were similar for the cervical cancer patients and healthcare professionals. . The patients provided individual-level barriers to appropriate health-seeking behavior that directly affect early detection, successful treatment, and management of the disease. The patient's statements were confirmed or corroborated with the health professional's perspective of the patient's individual level barriers and beyond. Throughout the interviews with the health professionals, the additional level of details on patients, the culture, health systems, and community aspects provided great contextual information to improve understanding of the patient's perspective. Participants perception of barriers were categorized into five major themes (1) knowledge and attitudes barriers, (2) cultural and religious belief barriers, (3) financial and structural barriers, (4) health system barriers, and (5) lack of community organization and government support barriers. Several of the sub-themes from patients and providers will be discussed in detail to add additional context to overarching themes. These barriers are related to strategies proposed to improve timely detection, treatment, and management of cervical cancer. These strategies will address barriers at each level of the SEM, individual, interpersonal, community, organizational, and societal level. There were four overarching themes that encompass strategies for improvement proposed by participants (1) cervical cancer education, (2) community outreach and sensitization, (3) health system improvements, and (4) community organizations and government support for cancer care.

Financial and Structural Barriers

The lack of development, infrastructure, low socioeconomic status, and financial stability of Ghana as a whole pose's significant barriers to cervical cancer care and outcomes. The financial issues of the individual affected their ability to seek proper diagnosis and, at times, their ability to continue treatment after diagnosis. The lack of social support by the husbands, families, and community members posed and issue at the interpersonal level. Because cervical cancer patient's family and communities don't know about the disease it is difficult to get financial and emotional support to endure the treatment and management of the disease. Financial and structural barriers were also very prevalent when assessing health system barriers at the organizational level. Lack of funding for different diagnostic services, trained workforce, standard equipment for treatment, cancer treatment centers in the regional areas of Ghana, and drug availability all played a role in healthcare facilities' ability to accurately diagnose, treat, and manage patients with cervical cancer. These financial constraints were even more prevalent in the Ghana Health Services; Community-based Health Planning and Services (CHPS), private hospitals, and district facilities were patients are often seen several times misdiagnosed and treated for other illnesses before being referred to the tertiary hospitals, further delaying proper diagnosis and treatment. The financial instability of the country as a whole with competing priorities from other infectious diseases such as malaria and HIV has prevented the government from providing the appropriate level of funding to the individual by way of adequate insurance. The lack of government-sponsored educational programs to promote community awareness for cervical cancer and timely reimbursement for hospitals insurance claims has prevented the ability of tertiary hospital to provide quality healthcare to cervical cancer patients.

Individual Level

The two significant barriers to appropriate health-seeking behavior, treatment adherence, and successful management of cervical cancer at the individual level cited by the patients and healthcare professionals were lack of knowledge of the disease and the financial and structural barriers. Most patients did not know about the disease before their diagnosis, and the majority of the women were not aware of the causes of cervical cancer even at the time of the interview. There is also a high level of illiteracy in Ghana that also creates a barrier when discussing knowledge. This is consistent with several other studies conducted in Ghana and other LMIC (Abotchie et al, 2010; Binka et. al, 2017; Tepera et al, 2019; Williams, 2014). At the time of the interview, the majority of participants were aware of the signs and symptoms of cervical cancer based on their experience but confused the symptoms with other feminine diseases before diagnosis. The patients admitted that the symptoms were unusual and strange to them, but not knowing the disease existed prevented them from urgently seeking care. When the symptoms continued and worsened after some time, then they go for medical care either on their own or because a family member suggested that they should see a doctor. Several of the women were referred to KATH, but due to financial cost to travel far from their homes with no transportation or accommodations, they delayed reporting to the hospital in Kumasi until they were able to gather money to travel. Once they arrive the lack of accommodations and access to proper nutrition makes it difficult for patients to continue treatment without interruption. The health professionals also cited knowledge and financial barriers as the key barrier hindering patients from seeking timely care at the individual level. Overall, the majority of patients probably presented early to district and community facilities for care. Due to financial constraints they end up lost to follow-up or they delay acting on the referral they received causing further delay. When they arrive in the tertiary facilities, they can't afford the diagnostic test and cost of treatment which often prevents successful management of the disease. A multi-level approach is necessary to improve timely diagnosis of cervical cancer, treatment outcomes and management of the disease. The patient's individual social needs, perceptions, and beliefs will need to be addressed to improve timely detection and treatment outcomes (Page et al. 2019).

Interpersonal Level

Most women only receive social support from their husbands, children, or other family members. The family and social network financial constraints often prevent them from fully supporting because of competing family priorities. Several of the health professionals stated that several women come alone for treatment and have no support from family or friends. Women feel that they must hide their disease from family and friends, forcing them to battle cervical cancer alone. A few stated that they receive help from their church, but members at the church have no idea what the disease is they have. Some women did not even tell their husbands or children because of fear that they would be abandoned accused of doing something terrible that caused them to have this disease. Similar findings were noted in several studies in the literature (Abotchie et al, 2010; Bateman et al, 2018; Binka et al. 2019). Most of the women interviewed receive financial support from their husbands, children, and other family members but admitted that other women in their villages would go home and die because they would not be able to afford the cost of the drugs or transportation to get to the tertiary hospital in Kumasi. The perceptions and beliefs of a women's social network and significant others will need to be considered to improve timely presentation and treatment outcomes. Their input directly influences the individual's decisions to seek care and affordability of care (Williams & Amoateng, 2012).

Normative gender relations were a cultural and religious sub-theme noted at the interpersonal level. The male spouse influences women when it comes to health-seeking behavior and ability to seek health care due to financial dependency on the male. Also, in some regions it is customary for the female to be examined by a female physician or only in the presence of male companion or family member if the vaginal region is involved. This often can delay when a woman seeks health care which delays the diagnosis and hinders the success of treatment outcomes. Several studies in the literature showed findings consistent with the present study. In order to address this issue males must be included in education interventions to better understand the disease and the need to support their partners emotionally and financially during treatment and management of the disease (Binka et al. 2018; 2019; Nartay 2018).

Community Level

The negative perception of cervical cancer in the communities prevents women from sharing their symptoms with family members and others in the community (Binka et al, 2017; Binka et al, 2019; Nartay et al. 2018). In Ghanaian culture, receiving a cancer diagnosis is like receiving a "death sentence." There is also stigma around the cervical cancer screening and vaccination. Women believe that they will not be able to have children if they get screened and if their children are vaccinated, they will become infertile. Most women are not aware of other women in their villages with the disease, so there is an overall lack of support due to fear of stigmatization associated with the disease. There is also a high level of misconception that cancer is contagious in African culture.

Lack of community knowledge poses a significant issue when it comes to social support as well. Women are hesitant to discuss their symptoms or diagnosis of the disease, so it is difficult to receive financial or emotional support from community organizations. Several studies in similar settings noted that there is a high-level of the stigma attached to chronic disease in LMICs so often disease state is not shared with others (Bateman et al, 2018; Nyblade et al, 2017). In Ghana, they feel that any disease that does not have a cure is considered a punishment (Binka et al, 2017). Fear of stigmatization and lack of community social support was noted by the cervical cancer participants and the health professionals as a major barrier to seeking care and continuing treatment.

Various cultural and religious beliefs directly affect health-seeking behavior that was noted by the participants. Often patients in African culture believe that a spirit or demon causes chronic diseases, or it is associated with witchcraft, so they seek traditional medicine first, or their pastor has to pray for them to be healed. Other women seek treatment from herbalist. It was noted during the interviews that cervical cancer patients feel more welcomed when they seek alternative healing than the hospital, so they opt to attend them first before seeking modern medicine. This is consistent with other studies conducted in Ghana and other West African countries (Bateman et al, 2018; Binka et al. 2019; Degarege et al. 2018).

Organizational Level

At the organizational level, there are several health system barriers noted by participants limited access to healthcare facilities and trained health professionals, lack of equipment and resources, negative experience with screening and treatment, several delays in receiving diagnostic reports, challenges in the referral process and follow-ups, lack of psychosocial support, no palliative care team, challenging patient navigation, and poor doctor-patient communication.. When you look beyond the individual the healthcare system as a whole poses a major barrier that hinders patients from receiving the appropriate level of care required to diagnose, treat and manage cervical cancer.

Health professional participants manage cervical cancer patients by providing several medical and other tangible supports. However, most reported that they do not collaborate well with other organizations and providers in the periphery, district hospitals, and CHPS compound who refer patients to them from the communities. This suggests that rural communities pose and even more significant barrier at the organizational level due to a lack of collaboration with tertiary facilities because of limited funding, equipment, and expertise to focus on cervical cancer populations. They also tend to prefer to operate as solo institutions, which causes delays in referral for diagnosis and treatment. Therefore, the external referral process from community health facilities to tertiary facilities poses a significant barrier in the successful treatment of cervical cancer patients beyond the individual and interpersonal levels. Patients and providers also noted lack of trained health professionals as a major issue. Several patients had surgery or was treated for several different diseases at the community or district level health facilities before presenting to the tertiary hospital without even receiving screening or official diagnosis of cervical cancer. Often when they present to the tertiary hospital, referral reports are incomplete and lack histopathology reports required for diagnosis. It was noted by some health professional participants that the referring facilities lack trained personnel to provide a proper diagnosis, and those that are trained in taking a biopsy do not have access to adequate health facilities (pathology) to obtain results, which further delays patients in presenting for care. The facilities that do have pathology services the results are delayed for several months due to lack of properly functioning equipment and staffing shortages. The literature supports the need for collaboration between community health facilities and tertiary governmental service providers to provide timely, comprehensive cervical cancer care to patients in the rural areas of Ghana (Kangmennaang et al., 2018; Ngcobo et al., 2019; Terpara and Dreyer et al., 2019; Williams-Brennan et. al., 2012;). It was noted in this study and other studies in the literature that the majority of the patients were coming from rural areas of the country and that low socioeconomic status is a known risk factor for cervical cancer (Binka et al, 2017 and Binka et.al 2019). This is the first study to suggest a need for formal external referral protocols to streamline services from the villages to the tertiary facilities to ensure continuity of service from the time of diagnosis, through treatment, and follow-up after treatment. Specialized education of health professionals in oncology is needed in the community health facilities and the tertiary facilities. It was noted by health professionals that there is a lack of specialized education across Ghana’s healthcare provider network.

Patient navigation including the internal referral process was also noted as a significant barrier by patients and the health professional. The participants felt that they must know someone that works at the facility to be able to navigate easily from one part of the hospital to another. Several patients are lost to follow-up even after coming from the peripheral facilities due to issues with the internal referral. Patients and providers mentioned that preferential treatment is given to patients who know an individual that works at the hospital. Several providers mention that internally in the hospital when patients are referred from one department to another the physicians very rarely communicate after the referral. Patients often have to be up early, even to be placed in the queue to see doctors. Family members are said to stand at the gate and run to the line for their ill family members to ensure they can be seen that day. The hospital was characterized by many of the participants as a scary place for patients that can be overwhelming for some to the point that they do not return due to wait times and the feeling of favoritism paid to other patients over them. In Ghana, the law currently states that no patient should be denied treatment. The hospital can write and exemption for the patient to be treated, but the delays in the approval process again leads to patients not being referred to the appropriate departments within the tertiary facility in timely manner and often are lost to follow-up. Patient navigation poses a significant issue for the successful treatment and management of cervical cancer patients. Patient navigation was noted as a significant issue in other studies conducted in similar settings (Binka et al. 2019; Lori et al.2018).

Patient and provider communication are a major issue for successful treatment and management of cervical cancer. It was noted by several providers that patients that do not see immediate results stop treatment, others that are feeling better think they are healed and do not return for treatment. Also, it was noted by both groups that doctors do not take time to explain test results, status of the disease, causes, side effects etc. to the patients. Patients were intimidated to ask questions of the physicians and the physicians are often short and impatient with the patients. The health professionals mostly noted this issue. The majority of the patients stated they like the interaction with health professionals and the nurses took great care of them. When reviewing this emerging theme to determine inconsistencies it was noted that patients made other statements that showed their hesitation in speaking to physicians. Also, several patients noted that they were not provided information about the disease, treatments, or progress which confirmed the issue of patient provider communication. This was consistent with other studies in the literature with similar population and setting (Fort et al., 2011; Mutyaba et al., 2006).

Culturally Ghanaian women are conditioned to endure pain. Therefore, assessment tools and palliative care teams are needed to provide education of palliative care and appropriate pain management for cervical cancer patients. It was noted that most patients were not in pain at the time of the interview, but several mentioned being in pain throughout the treatment process. Most of the health professionals mentioned that palliative care was a significant issue due to the lack of a specialized palliative care team. Also, the drugs to treat pain are not always in stock, so the cost is transferred to the patient even though it is supposed to be covered under the NHIS. Patients lack understanding of the palliative care. The World Health Organization defined palliative care as “an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through treatment of pain and other issues such as physical, psychosocial, or spiritual needs. It very important for patients to understand palliative care because some patients discontinue treatment when they do not see immediate results lowering their quality of life even further.

Similar findings were seen in a study conducted by Tarpera et. al. (2020) that suggest integration of oncology and palliative care policies in needed.

Cancer is a very debilitating disease due to the nature of the disease and the aggressiveness of the treatment and its many side effects. Many patients in Ghana lack family and community support that isolates them from society. Often patients are abandoned by their loved ones because of the financial burden of the disease and the stigma associated with the disease. This causes many psychological and emotional issues for the patient. The patients that are supported by their family often their loved ones experience emotional distress and mental instability. It was noted that the lack of psychosocial support is a significant barrier to successfully treating cervical cancer patients. Many of the nurses serve as counselors to try and console patients and the family members, but there is an overarching need for psychosocial support by health professionals trained in the discipline. Most of the physicians stated that they do not feel that the hospital can adequately address the psychosocial needs of the patients and provide them with the support they deserve.

A significant challenge for tertiary hospitals is that they are understaffed, lack state of the art equipment and the influx of patients that present in advanced stages increases the strain on the healthcare systems' ability to provide timely diagnosis, treatment, and management of cancer. Often the outdated machines break down, and it takes several days to repair. This delays treatment for patients. Some equipment can only administer treatment to one patient at a time, taking several hours often days to treat one patient. This makes scheduling patients for treatment very difficult and limits the number of patients that can receive treatment on any given day. This is consistent with previous findings (Leng et.al., 2020; Terpara and Dreyer et.al., 2019; Wu et al., 2017) which clearly stated that there are inadequate personnel and equipment to meet the demand for radiation therapy in lower-resource settings. Also, the patients felt that the health professionals often delayed their care, and the health professionals admitted that the lack of specialized trained workforce tends to delay care at the tertiary hospitals as well. Therefore, a common theme is professionals lack specialized cancer care knowledge at the organizational level in the peripheral health facilities, district hospitals and the tertiary hospitals.

Societal Level

Participants provided insight to the need for the government to provide funding to support resources and services; and develop policies and public laws geared towards universal education, vaccination, and mandated screening. Additionally, many patients and health providers spoke profoundly about the lack of involvement of non-governmental organizations in providing education and financial support for cervical cancer, similar to the support provided to breast cancer. Community organization and government initiatives ultimately are needed to ensure coordination of services, from the community health facilities to the tertiary hospital, suggesting that these gaps lead to a fragmented system in which resources are not available to provide successful treatment and management of cervical cancer. Inadequate insurances cause patients to have to pay for diagnostic testing, labs, and various treatments throughout their cancer care. For this reason, many patients do not complete the treatment or experience lapse in treatment that allows the disease to progress in the wrong direction.

Lack of timely reimbursement of the hospital by the National Insurance Scheme prevents the hospital from having the ability to stockpile drugs that are needed for treatment forcing the cost to be transferred to the patients. Cost to repair hospital equipment becomes a significant barrier when organizations are not reimbursed promptly. This causes significant delays in the treatment of patients. Several studies conducted in similar LMICs have shown that the burden on the healthcare system due to a lack of governmental support and policy regulations creates barriers to treatment and management of cervical cancer patients (Binka et al., 2019; Leng et.al., 2020; Nyambe et al., 2018). This study brings to light the need for timely reimbursement as a major factor for the health facility functioning at capacity in Ghana. Although the government covers certain medications under the health insurance the hospitals are not able to keep them in stock. These findings were not seen in the literature at the time of the study. The many health challenges and competing priority diseases such as malaria and HIV makes it difficult for the government to provide support at the level the disease requires. (Binka et al., 2019). Lack of knowledge of government officials, key decision-makers about cervical cancer and the burden of the disease leads to low levels of resources being allocated to the prevention and control of the disease.

Public Health Implications and Recommendations

The patients and their health providers proposed several solutions to barriers that affect cervical cancer care. These findings, coupled with evidence from peer-reviewed literature, have considerable public health implications and recommendations that cross all levels of the SEM. To better serve the people of Ghana, the government and non-governmental organizations must step in to provide resources required to improve the outlook of cervical cancer care. The challenges faced due to lack of infrastructure, low education and poverty must be taken into consideration. These underlying financial and structural barriers have influence at all levels of the SEM and must be considered when developing and implementing interventions, policies, and programs.

First, nationwide education of Ghana by Ministry of Health Ghana Health Services about cervical cancer causes, signs, and symptoms of the disease is a must. Findings from this study suggested that health professionals, women and men in the rural settings, and urban areas lack knowledge of this disease. The myths and misunderstanding of the disease being contagious or caused by a spirit or demon must be dispelled for the people to understand the importance of seeking care promptly and understanding why they must present to the hospital for treatment versus alternative medicine. The Ghanaian people need to understand the disease itself to buy into the need for prevention efforts such as vaccination of their children and routine screening for the women. Education is an essential first step in battling cervical cancer in Ghana. All participants stated education as a critical strategy for improving the timely detection of cervical cancer and treatment outcomes. Most patients felt that the women in their villages and community would see value in knowing the causes, signs, and symptoms of this disease, so they know to come to the hospitals early. Patients expressed great respect for health professionals and felt that they would be the best individuals to educate the people in the communities. All of the participants felt that if education were provided, it would help with the stigmatization and misconceptions the people have about the disease. Places noted that education and information session would be well received were churches, mosques, schools, and community centers.

It was noted that men should be included in all interventions especially education. In Ghanaian culture the male plays a big role in the financial stability and health seeking behavior of the women. Therefore, he must be knowledgeable of disease, causes, signs and symptoms as well. It is important that the men understand the need for screening and provide their women with financial support and encouragement to attend screening. Men also must have knowledge of the disease to better provide financial and emotional support to their partners throughout the diagnosis and treatment process. It was noted by several of the participants that women are often abandoned who have cervical cancer. Recent study conducted by Binka et al (2019) showed similar findings of abandonment of women with cervical cancer by men due to lack of understanding of the disease in addition to the financial burden of the disease.

It was suggested that social media and other communication channels such as TV, radios, videos, information vans and text messaging should be used to spread cancer awareness. Churches, schools, mosque, marketplace and community centers were noteworthy places mentioned to gather children, women and men to get the word out. Strategies to reach women in the more rural areas was different from the urban areas. Suggestions for women in the rural areas included the AM radio stations, posters in the villages, and community mobilization partnerships with leadership (i.e., queen mothers, chiefs, and councilmen) to bring the women together for education and potentially to screen as well. For women in the semi-urban areas, it was suggested that organizations such as the National Association of Beauticians and Hairdressers, icons in the community be used to spread the word about cervical cancer awareness. It was also suggested that in the more urban areas, it would be good to educate children in the first and second cycle schools who would ultimately share the messages with their family members and others. Young women could also be educated and vaccinated as a part of the entrance into the universities. The various methods of providing education have shown much success in the literature in Ghana and other low resource settings. (Ebu & Amissah-Essel et al., 2019; Nartey et al, 2018). This will build a sense of support that cervical cancer women need from their families and social networks. This will also prevent the high level of misconceptions and stigmatizations in the communities associated with the disease that causes women to shun away from their social networks when experiencing symptoms or after being diagnosed with cervical cancer. This is one of the first studies to highlight the potential use of social media applications and icons in the community to build awareness of cervical cancer in the more urban areas of Ghana given that most individuals have access to cellphones and internet.

During the time that individuals and their communities are being educated further to understand the disease and the need to seek medical attention promptly, health professional needs to be provided specialized training to detect the signs and symptoms of cervical cancer and refer early. The government must be ready to pass legislation to support the development of standard diagnostic facilities and well-equipped treatment and management facilities to provide access to the appropriate level of care required to combat this disease in the community health facilities and tertiary hospitals. This can be achieved through improved insurance premiums for patients to cover diagnostic tests and medication costs, timely reimbursement to hospitals for services rendered, and investment in building health infrastructure in the villages and communities in the more rural areas of Ghana.

Also, education standards and requirements set to improve the cancer care workforce regulated by the Hospital and Dental Council in Ghana are needed. Clinicians in the community setting must be trained to suspect cervical cancer because they are sometimes the first point of contact with the patients and often treat women for several illnesses before referring them to tertiary facilities when the disease has already progressed. Middle level personnel such as nurses and healthcare assistants must be trained to conduct screening in the communities and to refer early. Workshops and continued education training can be provided to clinicians, physician assistants, and nurses by qualified staff in the smaller hospitals and health facilities. Once there is improvement in knowledge a train the trainer approach could be potentially used to ensure a continued strong cancer workforce in the periphery areas of Ghana were most patients present first.

Regulations on messaging and information in the public domain about cervical cancer need to be regulated by the Food and Drug Boards. This will untimely increase overall public knowledge of the disease, which will improve social support symptoms for cervical cancer patients and their families who are directly affected by the disease. This will also decrease the false claims in the media by herbalist and other alternative medicine providers that they have products that can successfully treat cervical cancer. Again, without financial backing from the government and non-governmental community organization support, this will not be a feasible achievement for a low resource country facing many financial and structural barriers.

Next, the community organizations must advocate for cancer awareness at an early age to shift towards the implementation of prevention plans geared towards educating young women and young men in the school system about cervical cancer and implementing routine vaccination similar to hepatitis B and malaria vaccination policies (Finocchario-Kessler et al, 2016; Zarama et al., 2003). Community health nurses can use the time that women bring the children to be vaccinated as an opportunity to educate the women about cervical cancer, the need for vaccination of the children and screening for themselves. For this to be feasible, the government and community organizations must partner to ensure the availability of the vaccine and appropriate administration of the vaccine to males and females before the first sexual encounter (Centers for Disease Control and Prevention, 2019; World Health Organization, 2019). Because of the culture of Africa with early age marriages, research must be conducted to understand better the appropriate age of vaccination that is relevant to this particular setting. Additional research is also needed on culturally sensitive communication material given the level of stigma associated with sexual behaviors and the disease itself.

Healthcare organizations should consider as a high priority implementation of formal communication plans to improve the referral process from the villages. A referral hotline could potentially be implemented to facilitate continuous communication. The district and community health facilities should follow up to ensure patients referred actually make it to the tertiary facilities. The tertiary hospital should have a feedback loop of communication with the referring facility throughout the treatment and even after. This is important to ensuring that once patients' complete treatment and return to their villages they continue follow-up visits to detect any reoccurrence of the cancer in the early stages. This will also help referring physicians to better understand the need to refer additional patients who present with similar symptoms much earlier. Ultimately this will decrease the significant number of women lost to follow-up during the referral process. It will create opportunity for support from the government or community organizations to be provided to patients experiencing individual level barriers that delay them presenting for referred services.

At the same time, the government should invest in provider education at the community level to be able to screen women who are sexually active and treat patients in their home districts and rural settings to avoid the additional stress of traveling to the tertiary facilities without accommodations and adequate nutrition to sustain treatment. Given the length of time it takes to treat cervical cancer there is a need to develop a ward at the tertiary hospital to house and feed patients throughout the treatment process if they have to travel from the rural settings to receive treatment and management of the disease.

Healthcare organizations should also implement partnerships and formal referral processes with pharmacies and alternative medicine doctors, herbalists and traditional healers to educate them to understand better the need to refer patients early who present to them with symptoms of cervical cancer because they cannot treat this disease without a proper diagnosis. Healthcare organizations must also improve the internal referral process to ensure patient navigation is successful and less stressful for patients and their families from the diagnosis phase throughout the treatment and management process. Community liaisons can be put in place to assist patients with navigation through the healthcare process from diagnosis throughout treatment and follow-up. This could potentially lower the number of patients lost to follow-up from the initial referral in the peripheral hospitals to pathologist for diagnosis and then to the tertiary hospital for treatment.

Patients and provider relationships need to be improved to ensure that patients understand the causes of the diseases, the treatment they will receive the side-effects, and the importance of follow-up once the treatment is completed. Due to language and education barriers this is somewhat difficult and may require additional research to determine the best approach to bridge the communication gap between patients and providers. The hospital could possibly develop information centers in the hospital with materials in the native language or pictures to supplement the conversations that patients have with the doctors. This would allow patients and family members to obtain additional information at their leisure without the fear of asking questions to the physicians.

The addition of a psychosocial support team and palliative care teams can improve the overall care experience for patients with cervical cancer and their families. Ghana is a very spiritual country and therefore psychosocial support should include spiritualty in order to meet the spiritual needs of the patient Binka et al. (2018) study showed similar findings when assessing how patients in rural Ghana cope with having cervical cancer. This may potentially improve adherence to treatment and lower rates of patients lost to follow-up after treatment has begun.

Government, policymakers, and key stakeholders in Ghana must also be educated about the disease itself and the cost implications of providing funding for the treatment of the disease versus providing funding for education and prevention of the disease. Cancer in general is an inexpensive disease to treat if caught in the precancerous or early stages of the disease and can have very good prognosis. When the disease is diagnosed in the advanced stages it is very costly with poor outcomes. Often treatment is limited to palliative care. The government sponsored National Health Insurance Scheme can work internally with the tertiary facilities to improve timely reimbursement of services provided to patients. This will lead to more physicians ordering the appropriate diagnostic test for patients and conducting what is needed to provide the appropriate treatment without delay. This will also increase available funds for the health facilities to keep equipment updated and functioning properly to avoid delays in treatment.

A cultural shift towards the prevention of disease versus treatment is required to combat the high rates of morbidity and mortality and to improve overall health outcomes for women in Ghana. HPV vaccination should be considered for inclusion into the national immunization program in Ghana. Community-wide education is a must for women and men to better understand why there is even a need to get screening and present early for treatment. Community-wide education to understand the need for vaccination and access to the vaccine at low or no cost by child welfare services can potentially improve uptake.

Because of the many structural challenges faced by the Ghanaian people, the government will need to implement clear policies that define how cancer control will be implemented so that it is a top-down effect country-wide approach (Calys-Tagoe et al., 2020). It was recommended that the government could develop a policy to ensure that women are screened based on certain age categories. The Ghana National Identification Authority (NIA) implemented the National Identification System (NIS) to tract all citizens. This system could be used to develop a plan to screen all of the women that fall into a specific age category. These lists can be used to mobilize the appropriate group of women to screening. This could prevent a significant proportion of the women in the country from presenting with cervical cancer by tracking their screening through the NIS efforts. This also will significantly lower the cost to the government for treatment and management of the disease by lowering the number needing to be treated. In low resources countries, a multi-level approach will have a much more lasting impact than focusing only on the individual. Several strategies proposed by individuals who are experiencing this disease, coupled with proven interventions in the literature from similar LMIC, can provide the next steps to improving quality of life and health outcomes for cervical cancer patients and their families in Ghana (Binka et al., 2018; Binka et., 2019; Nartay et al., 2018).

Strength and Limitations

There are a few strengths and limitations to consider for this particular study. Based on a review of the literature at the start of the study, this is the first study to assess the healthcare professionals and the patient perspective using the social-ecological approach in Ghana to assess barriers to timely detection, treatment, and management of cervical cancer. Usual limitations associated with qualitative research, such as generalizability and reliability, were taken into consideration when drawing inferences from the data. Generalizability could be considered a potential limitation due to the study being conducted in one Ghanaian hospital on a small sample of patients and healthcare professionals. However, qualitative research often requires a smaller sample given the level of detail and work required for the study (Anderson et. al, 2010). To ensure we had a representative sample of the intended population, we selected a purposive sample with different characteristics from the standpoint of the disease of interest and relationship to the disease by including early stage and late stage cervical cancer patients and their healthcare providers. A purposive sampling strategy was useful in gathering the opinions of the target population. A large percentage of cervical cancer patients in Ghana are diagnosed and treated at KATH because it is one of the few tertiary hospitals in the region equipped to treat cervical cancer. Although data cannot be generalized to a larger population, data are considered transferable to a different setting. Therefore, generalizability is not a major factor in this study.

Transcription of notes was time-consuming and challenging to analyze. The careful design of the interview guide and pilot testing potentially minimized opportunity for error during the transcription phase. The inclusion of two researchers at minimum facilitation and recorder minimized issues around transcription. Another strength was the ability to utilize and iterative process to refine the interview guide throughout the interview to ensure information captured was accurate and relevant to the research questions. Also interviews continued until data saturation was reached meaning no new themes were emerging from participants.

Conclusions

The findings of the study highlight the importance of a multi-faceted approach to controlling public health issues in LMICs. Early detection of precancerous cells and invasive cervical cancer is a key aspect of successful treatment and management of the disease. However, women in Ghana usually present in later stages of cervical cancer as a result of the complex but interacting barriers. These barriers associated with an individual’s knowledge and attitudes towards the disease, health system access, policy constraints, financial issues, and structural challenges intersect with multiple levels of the socioecological framework. The synergistic interactions of these barriers make early detection of cervical cancer difficult in Ghana. Investments to improve the health system capacity in Ghana are required with a particular focus on strengthening the NHIS capacity to promote and ensure comprehensive healthcare coverage geared towards prevention efforts, and total cost of care across the continuum.

These findings also, provide opportunities for policies and practical interventions in cervical cancer management to be developed. These efforts should focus on investment in multi-level interventions geared towards cervical cancer education, community outreach and sensitization inclusive of screening and vaccination, health system improvements that include better equipped healthcare facilities by way of resources, treatment capacity and specialized trained workforce. The findings of the study further highlight the importance of overcoming community, organizational and societal level barriers in Ghana, which will have a more of a significant impact than only focusing on individual and interpersonal level factors. Given these findings, health promotion interventions seeking to improve practices regarding early detection of cervical cancer should take a multi-level approach that considers the current socio-cultural and political contexts within which the challenge of cervical cancer are constructed. These barriers must be addressed simultaneously to see improvement over time. It is pertinent that policymakers and stakeholders be educated to understand the cost of prevention would be much cheaper than the cost of treatment and management of cervical cancer. Understanding the barriers and strategies from the patient and provider perspective can shed light on the appropriate intervention, prevention programs and polices needed in Ghana to improve control of cervical cancer.

Future Research

Future research studies should be conducted in the peripheral more rural areas of Ghana to ensure that resources are allocated, and appropriate interventions target the communities who need it the most. Studies should also be conducted to test out the feasibility of implementing a patient navigation system that begins with the external referral process that guides the patient from diagnosis throughout the treatment process. Additional research is also needed to assess the needs for sex education and psychosocial support for women after treatment. It was noted in the findings of the study that often women struggle to cope with the physical changes in their bodies appearance and inability to perform or fear of performing sexually as they had prior to the treatment. Better understanding of the effects of treatment in this area may lead to additional strategies to improve the overall quality of life for cervical cancer patient survivors and their family members. Additional research is needed on the feasibility of utilizing the NIS to track and screen women for cervical cancer. This proposed method of improving prevention of cervical cancer was not seen in the literature and therefore should be further explored.

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APPENDICES

APPENDIX A: FIGO STAGING OF CANCER OF CERVIX UTERI (2018)

Stage	Description
I	The carcinoma is strictly confined to the cervix (extension to the uterine corpus should be disregarded)
IA	Invasive carcinoma that can be diagnosed only by microscopy, with a maximum depth of invasion <5 mma
IA1	Measured stromal invasion <3 mm in depth
IA2	Measured stromal invasion ≥3 mm and <5 mm in depth
IB	Invasive carcinoma with measured deepest invasion ≥5 mm (greater than Stage IA), lesion limited to the cervix uteri
IB1	Invasive carcinoma ≥5 mm depth of stromal invasion, and <2 cm in greatest dimension
IB2	Invasive carcinoma ≥2 cm and <4 cm in greatest dimension
IB3	Invasive carcinoma ≥4 cm in greatest dimension

Stage	**Description**
II	The carcinoma invades beyond the uterus but has not extended onto the lower third of the vagina or to the pelvic wall
IIA	Involvement limited to the upper two-thirds of the vagina without parametrial involvement
IIA1	Invasive carcinoma <4 cm in greatest dimension
IIA2	Invasive carcinoma ≥4 cm in greatest dimension
IIB	With parametrial involvement but not up to the pelvic wall
III	The carcinoma involves the lower third of the vagina and/or extends to the pelvic wall and/or causes hydronephrosis or nonfunctioning kidney and/or involves pelvic and/or para-aortic lymph nodes
IIIA	The carcinoma involves the lower third of the vagina, with no extension to the pelvic wall
IIIB	Extension to the pelvic wall and/or hydronephrosis or nonfunctioning kidney (unless known to be due to another cause)
IIIC	Involvement of pelvic and/or para-aortic lymph nodes, irrespective of tumor size and extent (with r and p notations)c

Stage	Description
IIIC1	Pelvic lymph node metastasis only
IIIC2	Para-aortic lymph node metastasis
IV	The carcinoma has extended beyond the true pelvis or has involved (biopsy-proven) the mucosa of the bladder or rectum. (A bullous edema, as such, does not permit a case to be allotted to Stage IV)
IVA	Spread to adjacent pelvic organs
IVB	Spread to distant organs

- When in doubt, the lower staging should be assigned.
- [an] Imaging and pathology can be used, where available, to supplement clinical findings with respect to tumor size and extent, in all stages.
- [b]The involvement of vascular/lymphatic spaces does not change the staging. The lateral extent of the lesion is no longer considered.
- [c] Adding notation of r (imaging) and p (pathology) to indicate the findings that are used to allocate the case to Stage IIIC. Example: If imaging indicates pelvic lymph node metastasis, the stage allocation would be Stage IIIC1r, and if confirmed by pathologic findings, it would be Stage IIIC1p. The type of imaging modality or pathology technique used should always be documented.

Source: Bhatla et al., 2018

APPENDIX B: RECRUITMENT AND INFORMED CONSENT LETTER – CERVICAL CANCER PATIENTS

Dear Participant,

You are invited to participate in a study conducted by Dr. Bettye Apenteng, Assistant Professor at Georgia Southern University (GSU), Georgia USA, in collaboration with Dr. Evans Afriyie-Gyawu (GSU), and Dr. Samuel Opoku (GSU), all of Georgia Southern University. The purpose of this study is to obtain the patient's perspectives on the progress made, as well as the challenges and opportunities associated with the clinical management of cervical cancer in Ghana. Your participation in this study will shed valuable insight on the facilitators and barriers to optimal disease treatment and management in times of resource scarcity.

For this study, you will participate in no more than a 60-minute interview discussing your experiences living with cervical cancer. Due to cancer being a sensitive topic, you may experience some emotional discomfort recounting your experience. If you feel you need someone to talk to, counseling services are available in the Oncology Unit, and we can refer you at no cost. You may also reach out to the Hospital Chaplaincy Unit at no cost, located in the Family Medicine Directorate of Komfo Anokye Teaching Hospital. The Hours: 7 am – 1 pm daily; On call for 24 hours/7 days a week. The telephone numbers are 0244932434 (Pastor Tony Oduro) and 0244465082 (Evangelist James Ofosu Mensah).

However, please note that you have the chance to opt-out of the study at any time. Your involvement in this research is **voluntary**; you may choose not to answer any question (s) for any reason. With your permission, the interview will be audio-recorded, responses will be kept confidential, only approved members of the research team will be able to read the transcripts created from the recordings. Your name will not be included to ensure confidentiality. You will receive 25GHC as a token of our appreciation to you for participating in this study.

Participants have the right to ask questions, and the research team will do their best to answer them. Should you have any questions or concerns, please contact the focus group facilitator or contact Dr. Afriyie-Gyawu [Phone #: 020-148-9155 (until August 31st, 2019, or; Email address: evansafriyiegyawu@georgiasouthern.edu]. This project has been reviewed and approved by the GSU Institutional Review Board (IRB H16458). For questions concerning your rights as a research participant, contact the Georgia Southern University Office of Research Services Sponsored Programs at +1 912-478-5465. The research team hopes that this study will highlight the opportunities and challenges associated with treating and managing patients with chronic conditions, especially when such care is rendered in a low-resource setting. Thank you for your participation!

Sincerely,

Bettye Apenteng (Principal Investigator)
PO Box 8015, 8x2416
bapenteng@georgiasouthern.edu

_____________________________________ __________________
Participant Signature Date
I understand and verify that the above-informed consent procedure has been followed.

_____________________________________ __________________
Investigator Signature Date

APPENDIX C: RECRUITMENT AND INFORMED CONSENT LETTER- HEALTHCARE PROFESSIONALS

Dear Health Care Provider,

You are invited to participate in a study conducted by Dr. Bettye Apenteng, Assistant Professor at Georgia Southern University (GSU), in collaboration with Dr. Evans Afriyie Gyawu (GSU), and Dr. Samuel Opoku (GSU). The purpose of this study is to obtain health providers' perspectives on the treatment and management of patients with chronic conditions in Ghana, including cancers such as cervical cancer. You have been invited to participate in this study because we believe you will shed valuable insight on the subject matter.

Your participation in this study is voluntary. If you do choose to participate, your involvement in this research will include participating in a 30-45-minute interview. The interviews will take place at your practice location. Interviews will be audio-recorded, but names will not be reported to assure confidentiality. It is not expected that there will be questions that cause discomfort. However, please feel free not to answer any questions you do not wish to answer. You may end your participation at any time.

Please note that data obtained, as part of this study, will be securely stored on GSU secure servers, and access will be restricted only to study investigators. All analyses and reporting of study findings will be done in aggregate, ensuring that the confidentiality of participants is protected. You will receive 25GHC as a token of our appreciation to you.

As a study participant, you have the right to ask questions and have those questions answered. Should you have any questions, please ask the person administering this survey or contact Dr. Afriyie-Gyawu [Ph: 020-148-9155; Email: evansafriyiegyawu@georgiasouthern.edu]. This project has been reviewed and approved by the GSU Institutional Review Board under tracking number (IRB H16458). For questions concerning your rights as a research participant, contact the Georgia Southern University Office of Research Services and Sponsored Programs at +1 912-478-5465.

The researchers hope that this study will highlight the opportunities and challenges associated with treating and managing patients with chronic conditions, especially when such care is rendered in a low-resource setting. Thank you for your participation!

Sincerely,

Bettye Apenteng (Principal Investigator)
PO Box 8015, 8x2416
bapenteng@georgiasouthern.edu

________________________________ ____________________
Participant Signature Date

I, the undersigned, verify that the above-informed consent procedure has been followed.

________________________________ ____________________
Investigator Signature Date

APPENDIX D: INTRODUCTORY QUESTIONAIRE - CERVICAL CANCER PATIENTS

Socioeconomic and Demographic Questionaire for Cervical Cancer Patient Participants

A. Name of Primary Researcher (Facilitator)
B. Name of Research Assistant (Notetaker/Recorder)
C. Secondary Research Assistant
D. Participant ID for Diagnosis Verification

1) Age (in year)
    a. 20–29
    b. 30–39
    c. 40–49
    d. 50–59
    e. 60+

2) Region of residence
    a. Urban
    b. Semi-urban
    c. Rural
    d. Non-Ghanaian residence
    e. Other

3) Education
    a. No formal school
    b. Primary school
    c. Secondary school
    d. Tertiary school

4) Occupation
    a. Teacher/businesswomen
    b. Seamstress/hairdresser
    c. Farmer/trader
    d. Unemployed
    e. Housewife
    f. Other

5) Family Monthly Income
    a. Low (GHC 0–600)
    b. Middle (GHC 601–1200)
    c. (≥GHC 1201)

6) Insurance
    a. Insured with adequate coverage for my condition
    b. Insured, but inadequate coverage for my condition
    c. Uninsured
    d. Other

7) Marital status
    a. Single
    b. Married
    c. Divorced
    d. Separated
    e. Widowed
    f. Living with a sexual partner

8) Age at menarche
    a. <12
    b. 13–14
    c. Above 14

9) Age at first intercourse
    a. <12
    b. 13–17
    c. 18 and above

10) Interval between menarche and first intercourse
    a. 1–2 years
    b. 3–4 years
    c. above 5

11) How many sexual partners do you have?

12) Contraceptive use
    a. Yes
    b. No

13) Do you douche?
    a. Yes
    b. No

14) What type of sanitary pads do you use?
    a.

15) Parity/number of children
    a. No children
    b. 1 – 3 children
    c. 4 – 6 children
    d. 7+

16) Religious beliefs
    a. Christian
    b. Muslim
    c. Traditional
    d. None
    e. Other

17) Family history of cervical cancer
    a. Yes (Type)
    b. No
    c. Do not know

18) Family history of other cancers
    a. Yes (Type)
    b. No
    c. Do not know

19) History of sexually transmitted diseases
    a. Yes
    b. No
    c. Do not know

20) Smoking habit
    a. Never smoked
    b. Current
    c. Former smoker

21) Alcohol
    a. Yes
    b. No
    c. Former

APPENDIX E: INTRODUCTORY QUESTIONAIRE - HEALTHCARE PROFESSIONALS

Health Professional Demographic Characteristics and Patient Population Served

Note: ID will be assigned to ensure proper matching with recording and to ensure that we can analyze data by specialty area.

The ID will consist of the first for letters of your specialty and the number in which you are interviewed within that specialty ***(i.e., The first nurse interview would be identified as NURS01, the second would be NURS02…..)***

Note: All information gathered during the interview shall be kept confidential. Data will only be presented in aggregate form.

1) Gender
    a. Female
    b. Male

2) Age (in year)
    a. 20–29
    b. 30–39
    c. 40–49
    d. 50–59
    e. 60+

3) Profession
    a. Doctor
    b. Nurse
    c. Community Health Worker
    d. Administrative Personal
    e. Psychologists
    f. Social Worker
    g. Other

4) Medical Specialty

5) Number of years in Health Care Services

Proportion of patients you provide care or services for with cancer

    a. None
    b. 1-20%
    c. 21 – 40%
    d. 41-60%
    e. 61-80%
    f. 80%+

6) Proportion of patients you provide care or services for with **cervical** cancer
    a. None
    b. 1-20%
    c. 21 – 40%
    d. 41-60%
    e. 61-80%
    f. 80%+

7) Marital status
    a. Single
    b. Married
    c. Divorced
    d. Separated
    e. Widowed
    f. Living with sexual partner

8) Religious beliefs
    a. Christian
    b. Muslim
    c. Traditional
    d. Other
    e. None

APPENDIX F: SEMI-STRUCTURED INTERVIEW AND FOCUS GROUP GUIDE - CERVICAL CANCER PATIENTS

Interview (Focus Group) Guide and Probes for Cervical Cancer Patient Participants

Interview/Focus Group Guide Instructions for Interviewer/Notetaker:

1) ***Please cover all topic areas***
2) ***There is no specific order that the questions must be asked***
3) ***You do not have to read all probes use them to facilitate the conversation or clarify a topic if the respondent does not seem to understand what you are asking***
4) ***Notetaker, please document all familiar verbal and non-verbal cues from the participant in your notes (i.e., body language, yes/no nodding, hand gestures, etc.)***
5) ***No more than three researchers to a room***
6) ***Place recorder close to the participant***
7) ***Do not open doors, shuffle paper, or talk near the recorder once the interview starts.***
8) ***At the start of the recording, please state the participants medical record ID and add to all documents (i.e., demographic questionnaire, notes, consent form, etc.)***
9) ***At the end of each topic area summarize the response and allow the participant to freely add additional relevant information, retract any statement that does not provide an accurate recount of their response, or confirm that your summary is true and correct.***
10) ***After each interview you conduct please transcribe them into English within 24-48 hours of the interview***

Begin Interview: Record Start Time

1) **Individual Level Knowledge, Attitudes and Beliefs about Cervical Cancer**

A. Please tell me what you know about the illness you have, which is now known to be cervical cancer?
   Probe:
   a. Is cervical cancer known by other names in Ghana?
   b. What were the first symptoms you had?
   c. What did you do when you recognized these symptoms?
   d. Are you aware of any other ***symptoms*** that women with cervical cancer have, what ***causes*** cervical cancer, or puts certain women at ***risk*** for cervical cancer?

B. Tell me, how did your symptoms make you feel when you first started having the symptoms?
Probe:
   1. When you first had the symptoms, did you feel you had a serious disease or just some common disease that did not require immediate attention?
   2. What did you do at home when these symptoms occurred?

C. What made you feel that you needed to seek care outside of your home (i.e., odor, pain, heavy bleeding, weight loss, etc.)?
   a. Have you received treatment for the symptoms at any other health facility before you came to Komfo Anokye Hospital for your symptoms? ***(If YES proceed to next question/If NO move to topic two)***
      i. Where else have you gone to seek care for these symptoms (i.e., health center, herbalist, etc.)? ***(If KATH was first location SKIP)***
      ii. Why did you go there for your symptoms? ***(If KATH was first location SKIP)***
   b. Were you referred to or told to go to Komfo Anoyke by another health care facility you went to for your symptoms? (***If KATH was first location SKIP)***
      i. How long did it take you to come to Komfo Anoyke from the time you were referred?
      ii. Why did it take you that time?

2) Individual Level Barriers to Timely Health Seeking Behaviour

A. Do you feel you should have gone to the hospital sooner?

B. What problems did you have that prevent you from going to the hospital when you feel you should have?

C. Does someone else in your family decide when you should go to the hospital or do you make this decision?

3) Interpersonal Influence and Social Network Knowledge of Cervical Cancer

A. Whom did you talk to when you suspected something was wrong with the symptoms you were having, and why did you tell that person? ***(If the participant responds no one skip to B.)***

Probe:

a. Did you talk to somebody you live with about your symptoms like a husband, mother, or sister, etc.?
b. Did you speak to someone at church, school, or work, etc.?
c. What did that person say to you about your symptoms when you told them?

B. If you did not tell anyone what made you keep the issue or symptoms from others?

C. Had you heard anyone in your community talk about having the symptoms you had or cervical cancer before you were told you have cervical cancer? ***(If no move to probe b.)***

Probe:

a. What did you hear them say about the symptoms of the illness of cervical cancer?
b. Did they talk about any other types of cancer? If so, what did they say?

4) Organizational-level Patient Knowledge and Experience with Cervical Cancer Screening

A. Have you ever been screened for cervical cancer?

B. What did you know about screening for your condition before you knew you had the condition? ***(Skip to topic five if never received screening)***

C. Tell me about your experience with the screening?

a. Where was the screening done?
b. What was done during the screening?
c. How long did you have to wait to be screened?
d. How long did the screening last?
e. How long did it take for you to get the results?
f. Where you required to buy or provide anything for the screening?
g. How much did you pay for the screening?
h. What kind of support did you receive from – family, friends, work, church, mosque, etc.?
i. What influenced you to accept the screening – How, why, when?

5) Organizational-level Patient Knowledge and Experience with Diagnosis and Understanding of Treatment

A. Tell me about your experience with being told you have cervical cancer at Komfo Anoyke ***(If diagnosed elsewhere insert name of facility)***?

B. What was the primary reason behind your visit (i.e., referral, pain, emergency, etc.)?

C. Who told you that you needed to have a test performed, and where was it done? How did you feel during the test?
   a. Who provided you with the results of your test (biopsy) and told you that you have cervical cancer?
   b. How did they tell you that you have cervical cancer (i.e., in person or by phone, etc.)?
   c. What were you told about your type and stage of cancer?
   d. When you came to this hospital, how long did it take to have the result of the test (biopsy) for cervical cancer back?
   e. Why did it take the time it took for you to receive the result?

D. What were you told about the symptoms in terms of causes, consequences, and management?

E. How do you feel about the health care workers you interacted with when you were told you have cervical cancer?

F. Did you have additional tests/procedures done on you at the time you received your test (biopsy) for diagnosis?
   a. What were you told about these procedures?
   b. How are the results of this test affecting you?

G. After receiving your cancer result, how long did it take you to receive the needed treatment?
   a. Tell us the time in days or weeks or months that passed from the time you got cancer result to time when you got the treatment you think was for treating the cancer itself
   b. Do you think that this kind of cancer can get cured?
   c. If you think it can get cured (or cannot cure), why do you think so?

H. What type of treatment have you been given?
   a. Chemotherapy, Radiotherapy, Surgery, Immunotherapy, LEEP, Hormone treatment, Bone marrow treatment
   b. Other (Specify)

I. Describe your experience and how you feel when you are given treatment?

J. What influenced your decision to get the treatment that you have received for your illness?

K. What information where you provided by Komfo Anoyke Hospital concerning options you may have for your cervical cancer treatment?

6) Palliative Care and Patient Support

Now lets us talk about your experience since you became aware that you have cervical cancer and began treatment?

A. Are you in pain because of your illness?
   a. What type of medication or support have you been given to manage your pain?

B. What kinds of support have you been receiving so far financial, washing, cooking, cleaning, assistance with shopping, conversation with friends?

C. What support have you received from social workers and community organizations?

D. Who has been supporting you - husband, children, friends, church mosque, etc.?

E. What advice have you been given by your health professionals nurses/doctors?

F. How do you feel about the health professionals you interact with for the treatment and management of your illness?

7) **Policy level Influence and Potential for Government-Mandated Community Outreach Programs**

A. What other experience would you like to share with other women to avoid cervical cancer?

B. What would you want to see changed in the way screening, diagnoses, and treatment are done in Ghana?

C. What type of activities would you like to see in your community to help other women learn about cervical cancer? Do you think other women would be interested in these activities?

D. Where do you think a woman would like to go to participate in these activities (schools, churches, community events, clinics, etc.)?

E. What would you like the government to do to promote women uptake of cervical cancer screening in Ghana?

Thank the participant for their participation and provide them with the 25GHC incentive. Notetaker document that the incentive was given to the participant and that you have the Patient Medical Record ID for diagnosis verification.

Record the time of completion

Note** Document the recording ID # to ensure correct matching of demographic data, patient recording, and transcription

APPENDIX G: SEMI-STRUCTURED INTERVIEW AND FOCUS GROUP GUIDE - HEALTHCARE PROFESSIONALS

Health Professionals Interview (Focus Group) Guide/Probes

Study Documentation

- **A.** Name of Primary Researcher
- **B.** Name of Research Assistant (Notetaker/recorder)
- **C.** Secondary Research Assistant (If required)
- **D.** Health Professional Unique ID

Interview/Focus Group Guide Instructions for Interviewer/Notetaker:

11) ***Please cover all topic areas***
12) ***There is no specific order that the questions must be asked***
13) ***You do not have to read all probes use them to facilitate the conversation or clarify a topic if the respondent does not seem to understand what you are asking***
14) ***Notetaker, please document all familiar verbal and non-verbal cues from the participant in your notes (i.e., body language, yes/no nodding, hand gestures, etc.)***
15) ***No more than three researchers to a room***
16) ***Place recorder close to the participant***
17) ***Do not open doors, shuffle paper, or talk near the recorder once the interview starts.***
18) ***At the start of the recording please state the participant's medical record ID and add to all documents (i.e., demographic questionnaire, notes, consent form, etc.)***
19) ***At the end of each topic area summarize the response and allow the participant to freely add additional relevant information, retract any statement that does not provide an accurate recount of their response, or confirm that your summary is true and accurate.***
20) ***After each interview you conduct please transcribe them into English within 24-48 hours of the interview***

Interviewer Record Start Time:

Health Care Professional Experience

1) Please tell me about your experience and practice as a health professional?
   Probe:
   a. What is your job or occupation title?
   b. How long have you been providing services in this area?
   c. What is the highest degree and certifications you have received?
   d. What is your current employment status?
   e. What types of services or care have you provided specifically to cervical cancer patients?

Provider Perspective of Perceived Barriers to Health-Seeking Behavior of Cervical Cancer Patients Individual/Interpersonal

2) Please tell me in your experience what the practical challenges faced by cervical cancer patients that determine health seeking behavior are?
   Probe:
   a. What challenges have you observed during your experience providing health care services to cervical cancer patients?
   b. What are the complaints you receive from patients and their family members?
      i. *Cost, transportation, hospital wait times, etc.*
   c. Are you aware of who decides for tests and treatments such as operations, to remove the uterus in cervical cancer patients?

    d. What role does the husband and other family members play in the patient's health-seeking behavior?
    e. Are you aware of any gender norms, social, cultural, and religious issues that affect health-seeking behavior in cervical cancer patients?
    f. What are the reasons that you are aware of that cause delays in decisions for operations and other treatment options from the patient perspective?

Organizational Barriers to Prevention, Early Detection, and Diagnosis of Cervical Cancer

3) Please tell me in your experience what you see as the challenges to timely detection and diagnosis of cervical cancer?

   Probe:
    b. Can you summarize the process for diagnosing cervical cancer?
    c. What do you see as the positive and negative factors that influence health-seeking behaviors, diagnosis, and Treatment in this hospital or community?
    d. What equipment and resources are available in the hospital or community for screening diagnosis of cervical cancer?
        i. Screening
        ii. Special cancer clinic
        iii. Pap smear
        iv. In-house pathology services
        v. Other
    e. What other resources are needed in your health facilities to accurately detect and diagnose cervical cancer?

Organizational Barriers to Cervical Cancer Management

4) What are the management challenges faced in this hospital or community?
    a. Tell us about your hospital or community referral processes from other facilities and internal referrals to different departments?
        i. Reason for referral
        ii. Patients "response to referrals."
        iii. How timely are patients with presenting to the facility referred to?
        iv. What %are lost to follow-up when a referral is required?

    b. What challenges are faced in providing follow up care to cervical cancer patients?
    c. What other resources are needed in your health facilities to accurately detect and diagnose cervical cancer?

Organizational Barriers to Cervical Cancer Management that affect Treatment

5) What are the problems/challenges facing cervical cancer management which undermine treatment outcomes?

   Probe:
    a. What are the physical and material needs of cervical cancer patients?
        i. In your opinion, what are some of the physical challenges that patients face under your care?
        ii. How do you deal with pain relief and symptom management among your cervical cancer patients? How available and affordable are the drugs that you use in this case?
        iii. What are some of the costs that your patients incur?
    b. In cases where patients have insurance cover, is it always adequate for their financial needs?
    c. How do you handle patients with serious financial challenges?

        - i. Is there any source of support you link them to?
    - d. What are the informational needs of cervical cancer patients?
        - i. In your opinion, do these patients need information regarding their disease treatment and care?
        - ii. If yes**,** do you meet those needs? And how do you meet them
        - iii. Information on managing illness side effects at home
        - iv. Benefits and side effects of treatment
        - v. Nutritional information
        - vi. Availability of support groups
        - vii. How promptly do you inform cervical cancer patients about their test results?
        - viii. Do you give explanations of those tests for which the patient would like explanations? If yes, how do you do this, and who does it?

Policy Level/Environmental Influences on Treatment and Management of Cervical Cancer

6) What policy-related efforts are ongoing or needed to improve the treatment and management of cervical cancer?
    - a. What are government-sponsored community-level interventions available to women with cervical cancer?
    - b. What hospital-based interventions do you think would help prevent cervical cancer in women?
    - c. What advocacy groups and organizational partnerships do you feel are needed to improve cancer treatment and management in Ghana?
    - d. What policies, insurance mandates, laws, etc. do you feel will help with cervical cancer prevention, treatment, and management?

Strategies for Improving Cervical Cancer Care in Ghana

7) In what ways do you feel these challenges can be overcome to improve treatment and management outcomes for cervical cancer patients?
    - a. Do you have other comments or concerns you would like to share from your personal or professional experience related to barriers or facilitators that affect the stage of cervical cancer at the presentation that we have not discussed?
    - b. Are there any other challenges to the treatment and management of cervical cancer patients that you have encountered when providing services that we have not discussed?

Thank the professional for their participation and provide them with the 25GHC incentive as a token of our appreciation. Notetaker document that the incentive was given to the participant.

Record Interview Stop Time