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PERCEPTIONS AND EXPERIENCES ABOUT CERVICAL CANCER SCREENING AND TREATMENT AT BATTOR, GHANA

BY

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DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree elsewhere.

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Supervisors' Declaration

We hereby declare that the preparation and presentation of this thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

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ABSTRACT

Cervical cancer is the leading cause of cancer mortality among women in Ghana and yet few studies have considered the psychosocial dimensions of the disease. The inadequacy of research is reflected in the lack of knowledge on barriers to screening and treatment of the disease among those infected and the general public. The main objective of this study was to explore the barriers to screening and treatment of cervical cancer among women in a rural setting in Ghana. The Socio-Ecological Model was used as the conceptual framework of the study. A qualitative design, using in-depth interview, focus group discussions as well as observation, was employed. Respondents consisted of cervical cancer patients, partners of cervical cancer patients, health personnel, women who have never been screened for cervical cancer as well as men from the study area. Interviews were transcribed and processed with the R Software package. The results revealed that patients had no knowledge of cervical cancer prior to being diagnosed. Those infected reported experiencing physical, psychological, economic and social disruptions to their lives due to the disease. Patients adopted personal, psychological and social coping strategies to manage the condition. Most male partners provided financial, social, material and emotional support to their spouses during the screening and treatment of the disease. The level of knowledge, attitude of health personnel, economic, socio-cultural and psychological factors were the main barriers to cervical cancer screening and treatment among the study population. Cervical cancer awareness creation, including screening and treatment opportunities and promotion of positive attitude of health personnel can reduce the threat of cervical cancer in rural communities.

KEY WORDS

Barriers

Biographical disruption

Cervical cancer

Coping mechanisms

Ghana

Human Papilloma Virus

Screening and Treatment

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DEDICATION

To my late father, Alex Komla Mensah and my loved ones, including my husband, Fred and children, Mawuena, Edem and Dzifa.

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LIST OF ACRONYMS

ACCP	American College of Clinical Pharmacology
ACS	American Cancer Society
ASR	Age Standardized Rate
CCP	Cervical Cancer Patients
CVD	Cardiovascular Disease
DNA	Deoxyribo Nucleic Acid
FGD	Focus Group Discussion
GHAG	Christian Health Association of Ghana
GHS	Ghana Health Service
HBM	Health Belief Model
HP	Health Personnel
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
IARC	International Agency for Research on Cancer
ICO	Institut Catala d'Oncologia
MFGD	Men's Focus Group Discussion
NCDs	Non-Communicable Diseases
OPD	Out Patient Department
Pap	Papanicolaou
PCCP	Partners of Cervical Cancer Patients
SEM	Socio Ecological Model
VIA	Visual Inspection Using Acetic Acid.
WFGD	Women's Focus Group Discussion
WHO	World Health Organization
WWHNS	Women Who Had Never Screened

CHAPTER ONE

INTRODUCTION

Background to the Study

Research indicates a growing incidence of cervical cancer among women (Denny, Kuhn, Hu et al., 2010; International Agency for research on Cancer [IARC], 2012; WHO, 2014). Despite the increase in the prevalence of the disease, rates of attendance to screening and treatment are low (Waller et al. 2009; Adanu, Seffah, Duda et al., 2010; World Health Organisation [WHO], 2013). Consequently, researchers have become interested in identifying and addressing the factors that prevent women from seeking cervical cancer screening and treatment (Lee-Lin, Pett, Menon et al., 2007; Sibaya, 2012).

Cervical cancer is a slow-developing disease that originates in the lower, narrow end of the uterus. It begins when normal cells lining the cervix transform to become abnormal, precancerous cells called dysplasia (WHO, 2014). Cervical cancer often develops for 10 to 20 years before becoming invasive. The slow-growing nature of cervical cancer allows for early detection and treatment, which can prevent the development of full-blown cancer (Szarewski, Jarvis, Sasieni et al., 1996). A complex interplay of biological, behavioural, interpersonal and social factors impact the uptake of cervical cancer screening and treatment (WHO, 2014).

There are several potential risk factors for cervical cancer, but the most prominent known cause is infection with the Human Papilloma Virus (HPV) (Green, Berrington de Gonzalez, Smith et al., 2003). Epidemiological studies carried out by some researchers including Zanotti and Belinson (2002) also confirm that Human Papilloma Virus (HPV) is a major risk factor for the development of pre-invasive or invasive cervical carcinoma. Hernandez, Wilkens, Zhu et al. (2008) state that men are the main reservoirs of genital HPV infection for women.

The virus can be spread through skin-to-skin contact, body fluid, and sexual intercourse (WHO, 2014). Most sexually active people will get HPV at some time in their lives, but often will never know because their body is able to fight it off (Botha, 2009). In some cases, however, the infection may persist, eventually causing cancer (WHO, 2014).

Since HPV is primarily transmitted through sexual activity, associated risk factors for cervical cancer include early marriage, multiple spouses and high parity (Anorlu, 2008). Limited education, increasing number of sexual partners, history of venereal diseases, and interval since last Pap smear (cytologic) test are also identified as risk factors (Chichareon, Herrero, Munoz, Bosch, Jacobs, Deacon, et al., 1998). In addition, a weakened immune system interferes with the body's ability to fight off HPV infections and early cancers. This is especially problematic for women with HIV who have HPV infection rates that are ten times higher than among HIV-negative women (Ramkisson, Searle, Burns, & Beksinska, 2010).

Cervical cancer is preventable with the use of screening tools (Murthy Pacak, & Loh, 2010). When cervical cancer is found in its early stages, it can be easily treated; however, treating advanced cervical cancer could be challenging (Murthy et al., 2010; Luciani, Jauregui, Kieny, & Andrus, 2009).

One method of primary prevention is the use of two HPV vaccines to protect against cancer-causing strains of HPV among girls 9 to 13 years

(WHO, 2013). The WHO recommends that this age group of girls should be targeted before they become sexually active. In high-income countries, the age group is between 9 and 25 years (WHO, 2013). According to Ramikisson, Searle, Burns and Beksinska (2010), HPV vaccination is the only realistic strategy for prevention as the vaccines have been studied in large populations and found to be safe, effective and well tolerated. However, they are mostly used in developed nations because of their high cost. Through the intervention of Global Alliance for Vaccines and Immunisation (GAVI) and other development partners such as UNICEF, the World Health Organisation, World Bank, and the Bill & Melinda Gates Foundation, some low-resource countries have been provided vaccines for use on pilot basis (GAVI Alliance, 2014).

In addition to vaccines, screening for early diagnosis and treatment of pre-cancerous lesions remain crucial (Botha, 2009). The most common screening method is the Papanicola (Pap) smear. This test involves the collection of cells from the surface of the cervix, which are viewed in a laboratory on a stained microscope slide to detect abnormalities (WHO, 2014). This is regarded as one of the most effective ways to determine whether a woman has cervical cancer or not (Duckitt, 2014).

Studies have shown that the incidence of the disease could be reduced by as much as 80 per cent with Pap smear coverage and follow up screening (Sankaranarayanan, Budukh, & Rajkumar, 2001). However, availability of laboratory equirement, test kits, follow up visits for results which sometimes delay or never released, misdiagnosis and cost, could be reasons why some women would not go for screening (Sankaranarayanan et al., 2001).

To overcome some of the challenges associated with the Pap smear, the use of the once-in-a-life time screening method known as the visual inspection with acetic acid (VIA) is now becoming a preferred option. The approach consists of naked eye visualization of the cervix after diluted acetic acid is applied to highlight areas of concern (Sibiya, 2012). The advantage of this procedure is that it requires only low-technology equipment and the result is immediately known. Treatment of abnormal lesions could be done during the same consultation. This could minimize the difficulties of follow up and resource procurement (Sibiya, 2012).

Another diagnostic tool that could be used in conjunction with Pap smear is the HPV test. This procedure checks cervical cells to determine if the cancer-causing types of HPV are present. Women with positive results are encouraged to go for annual Pap smear screening (Sibiya, 2012).

Ashford and Collymore (2005) and Zanotti and Belinson (2002) note that global efforts to detect cervical cancer have focused on screening women for abnormal cervical tissues, treating the condition before it progresses to advanced stages and providing appropriate follow-up care. Screening efforts have relied largely on Papanicolaou (Pap) smears to detect abnormal cell changes from the cervical transition zone (Juneja, Sehgal, Sharma, & Pandey, 2007).

According to Jeronimo, Morales, Horna et al. (2005), for low-income countries, the Pap smear test poses a number of challenges including, lack of trained cytotechnologists, shortage of cytology laboratories, long intervals between the Pap screening and making the results known and lack of health centres that are able to treat pre-invasive lesions. These challenges stimulated research on alternative tests, including Visual Inspection with Acetic Acid (VIA). This test has demonstrated high sensitivity for detecting cervical intra-epithelial neoplasm (CIN) (Jeronimo et al., 2005).

Due to the low awareness of cancer in Ghana, over 90 per cent of cervical cancer cases presented in health facilities tend to be at the advanced stage where the disease has already spread (MOH, 2011), putting cervical cancer incidence and mortality rates in Ghana among the highest in the world (Lingwood, Boyle, Milburn et al., 2008). These rates have been higher compared to the lower incidence and mortality rates in developed countries (Murthy, Pacak, & Loh, 2010).

Previous research has explored the importance of (i) demographic factors such as age, socio-economic status (Kelly et al., 2008; Louchini & Beaupré, 2008; Reis, Bebis, Kose et al., 2012; Williams & Amoateng, 2012); (ii) health-care factors such as appointment times, female practitioners, friendly treatment (Waller et al., 2009; Williams & Amoateng, 2012) and (iii) attitudinal factors like embarrassment, low level of knowledge of the disease, trust and concerns about discomfort (Agurto et al., 2004; Fort, Makin, Siegler, Ault, & Rochat., 2011). The studies conclude that the barriers to cervical cancer screening and treatment are modifiable and surmountable (Fort et al., 2011; Mahesh, 2013).

Targeted and sustained efforts towards the removal of the barriers to cervical cancer screening and treatment have been reported to be the driving force behind the decreasing incidence in prevalence and mortality in the United States (Moser, Patnick & Beral, 2009; Reis et al., 2012) and United Kingdom (Waller et al., 2009). Researchers suggest that the most effective method of reducing the incidence and mortality of cervical cancer is through screening and early treatment (Lee-Lin, Pett, Menon et al., 2007). There is therefore a growing consensus towards using multi-systems, multi-level and multi-disciplinary methods to studying cervical cancer screening and treatment (Ramkisson, Searle, Burns, & Beksinska, 2010).

Globally, cervical cancer is the fourth most common cancer and cause of cancer death among women (Lingwood, Boyle, Milburn et al., 2008; Jemal, Bray, Center et al., 2011; IARC, 2012). Each year, there are approximately 528,000 new cases of cervical cancer resulting in around 275,000 deaths of women in low-income countries (Sherris Wittet, Kleine et al., 2009; Jemal et al., 2011), with Sub-Sahara Africa (WHO, 2013) experiencing a higher proportion of the disease burden.

About 80 per cent of cervical cancer mortality occurs in low-income countries with 25 per cent in Africa (WHO, 2008). In addition, it is estimated that 78,879 women living in Africa will be diagnosed with cervical cancer annually, while 61,671 will die from the disease (Denny, Kuhn, Hu et al., 2010; Ferlay, Shin, Bray et al., 2010).

There is disparity in cervical cancer burden among regions with persons living in rural areas at a higher risk of cervical cancer compared to those in urban areas. These rural/urban differences have been reported in India (15% versus 5%), Ghana (10% versus 3%), and Nigeria (11% versus 5%) (IARC, 2012). Researchers have suggested that in order to stop the cervical cancer burden, there is the need to increase the use of cervical cancer screening tools and early treatment (Lingwood, Boyle, Milburn et al., 2008; Murthy, Pacak, & Loh, 2010; MOH, 2011).

Data from the World Health Survey indicate that cervical cancer screening rates in urban and rural areas in Ghana were 3.2 per cent and 2.2 percent respectively (Blumenthal, Gaffikin, Deganus et al., 2007; Domfeh, Wiredu, Adjei et al., 2008; WHO/Catalan Institute of Oncology [ICO], 2010). Despite these statistics, cervical cancer prevention is not commonly promoted in Ghana (Adanu, 2002; Boateng & Flanagan, 2008).

The results of previous studies by Blumenthal et al. (2007), Boateng and Flanagan (2008), Domfeh et al. (2008) and William and Amoateng (2012) indicate that lack of knowledge about cervical cancer among Ghanaians is a major barrier to cervical cancer screening. Ghana is currently not implementing any systematic national cancer programme and the development of a national cancer registry is at an undeveloped stage (MOH, 2011; Adanu, Seffah, Duda et al., 2010). As a result, there is no accurate estimation of the national cancer burden. Without accurate information about the regional distribution of cancers in the country, no realistic basis exists upon which to match the provision of cancer care with demand to ensure efficient resource use and equitable access to treatment, management and care (MOH, 2011).

Cervical cancer prevalence has been increasing in Ghana over the years. In the late 1990s, cervical cancer constituted 58 percent of all gynaecological cases reported at the Korle-Bu Teaching Hospital (Nkyekyer, 2002). In 2006, the IARC reported that 3,038 Ghanaian women developed cervical cancer and about 2,006 died due to cervical cancer (IARC, 2012). In 2008, out of 75 women visiting the Korle-Bu Teaching Hospital Gynaecology department, 7.5 per cent were affected with HPV DNA (Domfeh et al., 2008).

In Ghana, a number of studies have been conducted on cervical cancer (Nkyekyer, 2002; Adanu, 2002; Boateng & Flanagan, 2008; Domfeh et al., 2008; William & Amoateng, 2012). In spite of the contribution of researchers to the literature in Ghana and Africa, there are still gaps in cervical cancer knowledge in Ghana. These studies were mainly clinical studies (using data from only hospital systems), discipline specific (with a medical perspective) or focusing on individual perceptions about the disease and not the patients and their partners (Domfeh et al., 2008; Williams & Amoateng; 2012 Williams; 2014).

Considering the discourse on barriers to cervical cancer screening and treatment in both the developed and developing world, three fundamental research gaps are identified. The findings of these studies reported inadequate knowledge of cervical cancer among participants (Blumenthal et al. (2007; Waller et al., 2009). The studies focused more on the prevalence of cervical cancer and not the lived experience of patients of the disease which has various dimensions (Hoque & Hoque, 2009; Leung & Leung, 2010; Aswathy, Quereshi, Kurian, et al., 2012; Sudenga, Rositch, Otieno, et al., 2013; Abiodun, Fatungase, & Olu-Abiodun, 2014). Studies also focused on individual factors preventing screening and treatment rather than the multi-level inhibitors of cervical cancer screening and treatment.

Statement of the Problem

Information from the Reproductive Health Care Unit of the Korle Bu Teaching Hospital in 2009 indicates that cervical cancer accounted for about 75 per cent of all the cancers at the Unit that year. The incidence rate of cervical cancer in Ghana was 20 per cent and mortality rate at 80 per cent. WHO predicts that by the year 2025, there will be over 5,000 new cases of cervical cancer in Ghana and at least 3,300 cervical cancer deaths recorded annually (WHO/ICO, 2010). It is also estimated that about 60 to 70 per cent of women in sub-Saharan Africa who develop cervical cancer live in rural areas (Parkin, Ferlay, & Hamdi-Cherif, 2003), a finding that partly influenced the choice of location of the current study.

In spite of the reported incidence of cervical cancer, there is low awareness of the disease in the population. A study by Abotchie and Shokar (2009) among 140 female students at the University of Ghana between the ages of 20 and 35 showed that only 7.9 per cent were aware of the link between human papillomavirus and cervical cancer. Also, 70 per cent of the participants of the study had never heard of the disease and only half perceived themselves at risk. The low level of awareness of the disease results in low screening and delay in seeking treatment (Downs, Smith, Scarinci, Flowers, & Parham, 2008).

A study by Abotchie and Shokar (2009) among female university students in Ghana showed that only 12 per cent out of 140 women interviewed had ever been screened for the disease. A survey conducted in the Greater Accra region by Adanu, Seffah, Duda et al. (2010) also showed that only about 2 per cent of women have had cervical cancer screening through Pap smear. Although the women perceived the benefits of screening, the lack of belief that cancer is diagnosed through cervical screening, belief that the test is painful or will take away their virginity prevented them from screening. There is also the absence of a national survey on cervical cancer. The absence of data prevents the identification of the factors that hinder cervical cancer screening uptake.

In cases where women visit health facilities for cervical cancer screening, some of them do not return for follow up consultations for various reasons, including high cost of treatment, long waiting time, attitude of health workers, cultural and social norms (Adanu et al., 2010). These practises increase the women's risk. Nearly 60 to 70 of cervical cancer cases appear among women who have never been screened or do not adhere to screening guidance (Downs et al., 2008).

Furthermore, the health care system has limited capacity to offer treatment such as radiation combined with chemotherapy for more advanced cases of cervical cancer (Adanu et al., 2010; Vuhahula, 2004). Access to health care in the country is affected by a complex set of interacting factors. Among them are the social environment, health-seeking behaviours, socio-economic background, cultural beliefs and values (Williams & Amoateng, 2012).

In the absence of a national survey on cervical cancer, the factors that hinder cervical cancer screening uptake will remain unknown. A survey conducted in the Greater Accra region, for example, showed that only about 2 percent of women have had cervical cancer screening through Pap smear (Adanu et al., 2010). Overcoming these barriers would need an understanding of the fears and concerns of women, the experiences of infected persons and their partners and community perceptions.

For effective cervical cancer prevention and control, it is important to identify the barriers to cervical cancer screening and treatment from the perspectives of patients, their partners, health workers as well as women who had never screened despite the existence of screening programmes, even when they have access to screening services.

Objectives of the Study

The main objective of the study was to assess perceptions and barriers to screening and treatment of cervical cancer among rural women in Ghana.

The specific research objectives were to:

1. Assess the knowledge, perception and experiences of women living with cervical cancer;
2. Explore the coping strategies adopted by cervical cancer patients;
3. Determine the factors that constrain cervical cancer screening and treatment uptake; and
4. Examine the knowledge and role of male partners in cervical cancer screening and treatment.

Significance of the Study

Although attention to non-communicable diseases (NCD) research is increasing, cancer research receives less attention and investment in Africa. There is inadequate knowledge about cancer patterns and sparse population based epidemiological data on incidence and prevalence levels (Pisani, Bray, & Parkin, 2002). Studies carried out on cervical cancer in Ghana over the years have been clinical in nature and mostly focusing on prevalence of the disease (Adanu, 2002; Nkyekyer, 2002; Wiredu & Armah, 2006). There is also no evidence of any study carried out in Ghana that focused on women with cervical cancer, survivors of the disease and their partners. Studies carried out on cervical cancer were focused on non-cervical cancer patients (Hoque & Hoque, 2009; Leung & Leung, 2010; Aswathy, Quereshi, Kurian, et al., 2012; Sudenga, Rositch, Otieno, et al., 2013; Abiodun, Fatungase, & Olu-Abiodun, 2014).

Few studies in Ghana have centred on barriers to uptake of cervical cancer screening and treatment (Williams, 2014; Ebu, Mupepi, Siakwa, & Sampselle, 2015). Findings from this study will supplement the literature on barriers to cervical cancer screening and treatment in the country. Also, there is virtually no study carried out on coping strategies adopted by cervical cancer patients in managing the disease in Ghana.

There is therefore a gap in knowledge regarding other dimensions of the disease such as barriers to screening and treatment and experiences of patients. Findings from this study will provide information on the various aspects of the disease in terms of personal experiences, perceptions as well as opinions of respondents in the study by focusing on the lived experiences of cervical cancer patients as well as their partners. In addition, a study on coping strategies adopted by cervical cancer patients and their families in managing the disease can be deployed to manage the disease. The study is also expected to generate knowledge on the role played by partners and their understanding of the disease prior to and after the diagnosis of their partners.

Organisation of the Study

The thesis is divided into nine (9) chapters. The first chapter provides a background to the study, statement of problem, research objectives, significance of the study as well as organisation of the study. Chapter Two presents the review of related empirical literature while Chapter Three focuses on models on health seeking behaviour.

The fourth chapter describes the methods of data collection and analyses. These include the study area, the research design, population, sampling procedure, data collection instruments, ethical consideration, pretesting, fieldwork, field experiences, data quality control, data analysis and limitations of the study. Chapter Five assesses the knowledge of women on cervical cancer – causes and risk factors. Chapter Six focuses on challenges to the uptake of cervical cancer screening and treatment. Coping strategies adopted by patients in managing the disease are analysed in Chapter Seven. Chapter Eight examines the knowledge and role of male partners in cervical cancer screening and treatment. The final chapter gives a summary of the thesis, draws conclusions and makes recommendations based on the findings of study. The chapter also provides direction for future research.

CHAPTER TWO

EPIDEMIOLOGY AND PERSPECTIVES ON CERVICAL CANCER

Introduction

This chapter presents a review of related literature on the epidemiology of cervical cancer globally, in terms of the prevalence, aetiology and pathogenesis of the disease, the various stages of the disease as well as factors that account for the disease. It also presents related literature on other perspectives on the disease including coping mechanisms adopted by cervical cancer patients and barriers to uptake of screening and treatment of the disease.

Incidence, Prevalence, Mortality, Control and Prevention of Cervical Cancer from a Global Perspective

Observed disparities in incidence of cervical cancer and mortality are largely accounted for by inequalities in cervical cancer screening (WHO/ ICO, 2010). In countries with well-organized screening programmes, rates of cervical cancer morbidity and mortality have declined over the past decades (Franco, Duarte-Franco, & Ferenczy, 2001). In some low-income countries, cervical cancer is not recognised as a public health priority and screening programmes are mostly opportunistic. As a result, the incidence of cervical cancer remains unchanged (Arbyn, Raifu, Weiderpass, & Anttila., 2009; IARC, 2012).

Notwithstanding the availability of effective methods for prevention, cervical cancer is the fourth most common cancer among women in the world with an estimated 528,000 cases in 2012 (Table 1). About 85 per cent of the global burden of cervical cancer occurs in less developed regions. This represents almost 12 per cent of all female cancers (International Agency for Research on Cancer [IARC], 2012).

Table 1: Cervical Cancer Incidence, Mortality and Prevalence Worldwide by 2012

Region	Incidence	Mortality	5-year Prevalence
World	528,000	266,000	1,547,000
More developed regions	83,000	36,000	289,000
Less developed regions	445,000	230,000	1,258,000
Africa	92,000	57,000	236,000
America	83,000	36,000	279,000
Europe	67,000	28,000	225,000
East Mediterranean	15,000	8,000	42,000
South-East Asia	175,000	94,000	465,000
Western Pacific	94,000	43,000	299,000

Source: IARC, 2012

High-risk regions with estimated age standardized rate (ASR) over 30 per 100,000, include Eastern Africa (42.7), Melanesia (33.3), Southern (31.5) and Middle (30.6) Africa. Rates are lowest in Australia/New Zealand (5.5) and Western Asia (4.4). Cervical cancer remains the most common cancer in women in Eastern and Middle Africa (IARC, 2012).

Given the effectiveness and direct public health impact, the cytology-based Papanicolaou (Pap) test has been cited as one of the top ten public health achievements of the 21st Century (Peto, Gilham, Fletcher, et al., 2004;

Arbyn, Raifu, Weiderpass et al., 2009; De Kok, van der Aa, van Ballegooijen et al., 2011; Dijkstra, Snijders, Arbyn, Rijkaart, Berkhof, & Meijer, 2014). Literature reviewed shows that even though cervical cancer is one of the infectious and deadly cancers among women in the world, high-income countries have been able to bring the disease under control through screening and use of the HPV vaccine. On the other hand, women in low-income countries continue to die in the absence of programmes to encourage cervical cancer screening and treatment.

Incidence of Cervical Cancer, Prevalence, Mortality, Control and Prevention in Africa

High incidence of cervical cancer are reported in Africa at rates exceeding 50 per 100 000 population as of the year 2000 (WHO/ICO, 2010). In 2012, the incidence of cervical cancer was estimated at 93,225, accounting for 25.2 percent of all cancers among women and only second to the incidence of breast cancer which is at 25.5 per cent of all cancers among women (IARC, 2012). It is the highest cause of cancer-related death among women representing 23.2 percent of all cancer deaths among women, followed by breast cancer deaths with 19.3 percent. This translates to an incidence and mortality rate of about 35 and 22 per 100,000 persons per year respectively (IARC, 2012).

In sub-Saharan Africa, the incidence of cervical cancer was estimated at 93, 225. This accounted for 25.2 per cent of all cancers among women and is second only to breast cancer with a rate of 25.5 per cent of cancers among women (IARC, 2012). It is the highest cause of cancer-related death among women, representing 23.2 per cent, followed by breast cancer deaths with 19.3 per cent.

In Western Africa, cervical cancer ranks first among cancers in women. It is estimated that about 27,326 new cervical cancer cases were recorded in 2012, representing 24.2 per cent (ASR 29.3 per 100,000) of all new cancer cases among women (IARC, 2012). In terms of cancer related deaths, cervical cancer is estimated to have the second highest number of 16,546 deaths (22.5%) for all cancers among women. The age-standardised mortality rate of cervical cancer is 18.5 per 100,000 persons per year and second to breast cancer (IARC, 2012). Africa appears to be a major risk region in terms of cervical cancer prevalence and mortality. Annually, it appears more women seem to contract and die from the disease. This is a cause for concern that must be addressed by researchers, public health experts, policymakers, Non-Governmental Organisations (NGOs) as well as governments in Africa.

Overview of Cervical Cancer in Ghana

Women in Ghana, like other countries, continue to suffer from cervical cancer though it can be prevented and treated, if detected early. Figure 1 presents a summary of the cervical cancer incidence in Ghana. It is estimated that about 3,052 new cervical cancer cases were recorded in Ghana in 2012. This represents 32.7 percent of the total cancer cases among women in the country (IARC, 2012). Cervical cancer still tops the list with 7,749 cases in 2012, representing 34 per cent of all cancer cases among women in the country.

In 2000, it was reported that cervical cancer was the leading gynaecological problem seen at the Korle-Bu Teaching Hospital (Nkyekyer, 2002). By 2012, cervical cancer topped the list of cancer deaths of about 1,556, representing 28.2 per cent of all deaths due to cancers in 2012, among women in the country (IARC, 2012). This shows that cervical cancer is still the leading cause of cancer death among women in Ghana, and yet it does not attract the needed attention. The situation calls for both preventive and curative measures to minimise the deaths among women and to make it possible for those with the disease to have treatment and support.

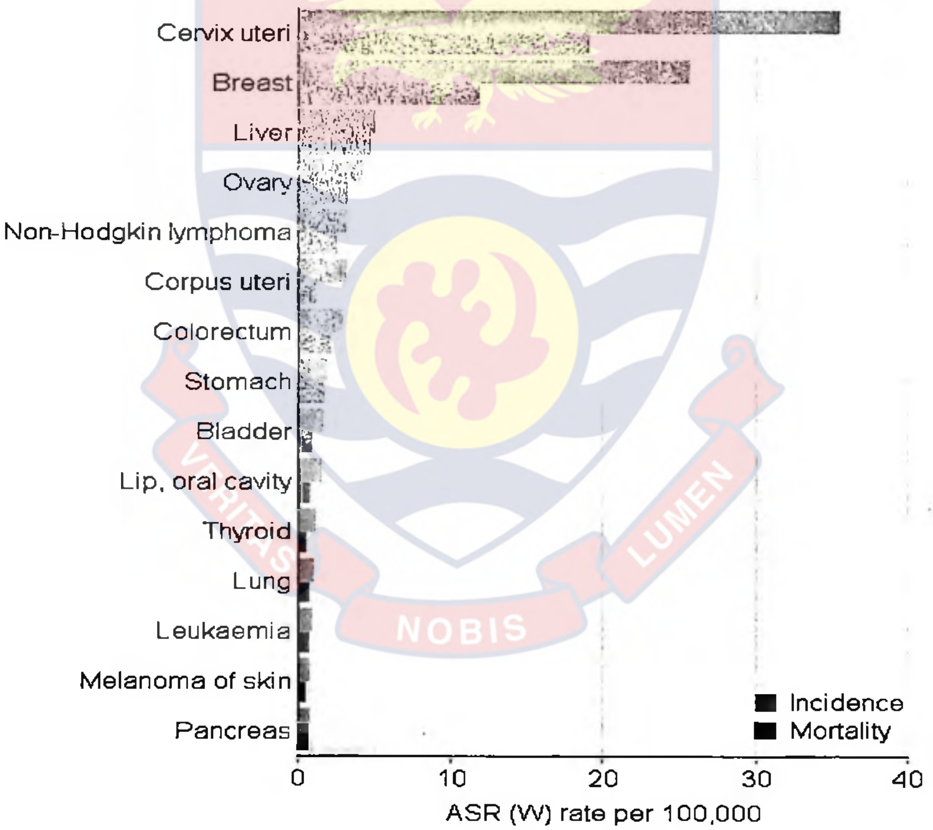


Figure 1: Incidence of Cervical Cancer Compared to all Other Cancers among Women of All Ages in Ghana in 2012.

Source: IARC (2012).

National Strategy for Cancer Control Policy in Ghana: 2012-2016

The first national policy on cervical cancer prevention was developed in 2005 as part of the National Reproductive Health Policy (MOH, 2011). This policy recommended screening for cervical cancer with Visual Inspection with Acetic Acid (VIA) along with treatment of pre-cancerous lesions with cryotherapy for women aged 25-45 years and Cytology screening with PAP smear for women aged 45 and above (MOH, 2011). The national screening programme was never fully carried out (MOH, 2011). The inability to fully implement the recommendations of the policy could be attributed to factors including inadequate screening and treatment centres, lack of qualified health personnel to provide the necessary services; limited data on the disease and ignorance about the disease which leads to late reporting (MOH, 2011).

Currently, screening using VIA is carried out at the Korle-Bu Teaching Hospital (Accra), Ridge Regional Hospital (Accra), Komfo Anokye Teaching Hospital (Kumasi), the Catholic Hospital in Battor (Volta Region) and La General Hospital (Accra). Cervical cancer screening, using Pap smear is also done at a few private health facilities and laboratories (mostly in urban settings) at a high cost that cannot be afforded by a lot of women.

In the year 2011, the total number of women screened at both the Ridge Hospital in Accra and Komfo Anokye Teaching Hospital (KATH) was 770. Of these, 28 (3.6%) were identified to be VIA positive. In all, a total of 24 (86%) cryotherapies were performed. For 20 years, Ridge clinic has been providing HPV vaccinations (Cervarix) at a cost of GHC85.00 per dose (Ghana Health Service, 2014).

In Ghana, the Ministry of Health adopted a new National Strategy for Cancer Control (2012 – 2016), which outlined plans for cervical cancer control (MOH, 2011). The plans are based on three (3) areas: prevention, screening and treatment. Under prevention, HPV vaccine would be offered for all females from 10 to 14 years of age. The approach is to target in and out-of-school girls for vaccination and providing community-based immunisation routinely through the existing Expanded Programme for Immunisation (EPI).

For screening, the plan advocates that all women at risk of cervical cancer are to be screened for early detection of precancerous cells. The plan proposes public education on cervical cancer and raising awareness on regular screening. In terms of education, the plan hopes to provide general awareness on the causes, symptoms and signs and prevention through safe sex and vaccination. The plan also seeks to create awareness on the available health facilities for screening and treatment.

Screening is also to be integrated into the existing reproductive health programmes (MOH, 2011) in line with WHO (2013) recommendations that every woman between the ages of 30 - 49 years should be screened, at least once in her lifetime. Studies have shown that screening women once or twice, between ages 35 and 40, can lower women's lifetime risk of cervical cancer from 25 per cent to 35 per cent; conducting three lifetime screenings would reduce risk by more than 50 per cent (Williams, 2014; Ebu, Mupepi, Siakwa, & Sampselle, 2015).

Under treatment, the plan suggests surgery or radiation therapy for early stages of the disease and chemo-radiation for the advanced stage (MOH, 2011). Treatment of diagnosed precancerous lesions is to be ablative or excisional while cryotherapy and LEEP are recommended as out patients options (MOH, 2011).

Though cancer control policy is in its third year in Ghana, it is yet to fully take off. The delay could be attributed to a number of reasons including the inability of the Ghana Health Service to decentralise the screening and treatment services. There is also no organised system in place for follow up of patients. The situation seems to be further complicated by the fact that the National Health Insurance Scheme (NHIS) does not cover screening for diseases.

The 2012–2016 Strategy for Management, Prevention and Control of Chronic Non-Communicable Diseases (MOH, 2011) recommends that women attending health facilities should be opportunistically screened for cervical cancer while women above 35 should undergo visual inspection of the cervix acetic acid (VIA) or Lugol’s iodine (VILI) at designated health facilities. This strategy is also not being fully implemented for various reasons, including limited screening facilities and health professionals (MOH, 2011; Adanu et al., 2010; Williams, 2014).

The 2013 Annual report of the Non Communicable Diseases Control Unit of Ghana also presents a long list of challenges the Unit faces, including lack of national screening programmes for various cancers, including cervical cancer, trained staff, limited diagnostic or screening equipment, inadequate or absent treatment guidelines and high cost of medical care. The report indicated that the Ministry of Health now has centres in four of the 10 regions, but they are yet to start functioning due to financial constraints.

A previous Cancer Policy launched in 2005 was also not able to deliver on cervical cancer prevention programmes and treatment for women (Adanu et al., 2010; Williams, 2014; Ebu, Mupepi, Siakwa, & Sampselle, 2015). The Ghana Health Service (GHS) has classified screening services delivered as opportunistic and since few women have regular check-up, the majority of them might not be screened (Adanu et al., 2010; Ebu, Mupepi, Siakwa, & Sampselle, 2015).

Aetiology and Pathogenesis of Cervical Cancer

Clinically, cervical cancer is defined as a type of cancer that forms within the tissues of the cervix. The cervix connects the uterus with the vagina (birth canal) (National Cancer Institute, 2015, American Cancer Society, 2015a). It is usually a slow-growing cancer that may not have symptoms but can be found with regular Pap tests (a procedure in which cells are scraped from the cervix and looked at under a microscope) and is almost always caused by human papillomavirus (HPV) infection (National Cancer Institute, 2015).

The part of the cervix closest to the body of the uterus is called the endocervix while the part next to the vagina is the exocervix (or ectocervix). There are two main types of cells covering the cervix: the squamous cells are located on the exocervix while the glandular cells are located on the endocervix, and they meet at a place called the transformation zone which changes as one ages and gives birth (American Cancer Society, 2015a).

Cervical cancer can be classified based on where it originates in the cervix. The most common type of cervical cancer is defined as squamous cell carcinoma, having originated in the ectocervix or the side facing the vaginal canal. Adenocarcinomas are cervical cancers that develop in the endocervix or portion of the cervix facing the uterus. Cervical cancer that originally involves both the ectocervix and endocervix are usually classified as adenosquamous carcinomas or mixed carcinomas (Bosch, Burchell, Schiffman et al., 2008, American Cancer society, 2015a).

Persistent infection with one or more oncogenic subtypes of Human Papillomavirus (HPV) is a necessary, but insufficient cause of cervical cancer (Bosch et al., 2008). There are more than 100 identified subtypes of HPV, of which at least 15 are considered to have oncogenic potential (Bosch et al., 2008). Globally, oncogenic HPV subtypes 16 and 18 are the most prevalent, and are implicated in at least 71 per cent of all invasive cervical cancer cases (de Sanjosé, Quint, Alemany et al., 2010; Li, Franceschi, Howell-Jones et al., 2011). Invasive cases of cervical cancer associated with HPV subtypes 16, 18 or 45 are reported to be present at a younger mean age compared to those with other types of HPV (50·0 years, 48·2 years, 46·8 years) (de Sanjosé et al., 2010).

The Human Papilloma Virus (HPV) is considered to be the most common sexually transmitted infection (Bosch et al., 2008). Worldwide, it is estimated that at any given time, more than 10 percent of women with normal cytology harbour HPV infection (Clifford et al., 2005; de Sanjose et al., 2007). Though infection with one or more oncogenic types of HPV has been established as a necessary precursor to most cervical cancers (Wilyman, 2011), fewer than 10 percent of persistent HPV infections progress to carcinoma in situ (Rositch, Koshiol, & Hudgens, 2013), which, if left untreated, can progress to cervical cancer (Kulasingam, Havrilesky, Ghebre, & Myers, 2011).

It has been noted that progression of HPV to cancer requires additional factors, which remain poorly defined (Cogliano, Baan, Straif et al, 2011). Cervical cancer seems to develop gradually without clear symptoms for a long time. As a result, many women who may be infected with the disease may not be aware until it develops into an advanced stage. The delay in the advancement of the disease provides an opportunity for education of women to go for screening. For this to happen, the services should be accessible and affordable.

Signs and Symptoms of Cervical Cancer

Early cervical cancer may not produce noticeable signs or symptoms. Possible signs and symptoms are vaginal bleeding after sex, in-between periods or after menopause (WebMD, 2015; American Cancer Society, 2015a). However, in most patients, there may be no symptoms at all whatsoever until the disease is at the last stage. Other symptoms of cervical cancer include vaginal pain especially during sex, unpleasant-smelling vaginal discharge, vaginal discharge stained with blood, bleeding from the vagina which is not normal, change in menstrual cycle that cannot be explained and pain when passing urine (WebMD, 2015; American Cancer Society, 2015a).

In advanced cervical cancer, when it has spread into surrounding tissues, it can trigger additional symptoms such as constipation, blood in urine, urinary incontinence, bone pain, swelling of legs, tiredness or loss of appetite (WebMD, 2015). The fact that signs and symptoms of the disease do not manifest until the disease has reached the latter stage, has severe implications for women's wellbeing that must be of concern to health service providers. This is because a number of women may be living with the disease without knowing it and the only sure way to know would be through regular screening.

Risk Factors of Cervical Cancer

Several factors have been found to predispose women to cervical cancer. These include sexual, reproductive, lifestyle factors and health status. In particular, early sex, multiple pregnancies and multiple sexual partners increase HPV exposure and infection (Mahesh, 2013; Rousseau, Franco, Villa et al., 2000).

Sexual Risk Factors

According to the WHO (2013) and Baseman and Koutsky (2005), sexual activity is the predominant risk factor for HPV infection. The peak time of infection is shortly after initiating sex (WHO, 2013). Majority of these infections, however, resolve spontaneously and do not cause symptoms or disease. Persistent infection with 16 and 18 types of the virus may lead to precancerous lesions, which, if left untreated, may progress to cervical cancer (WHO, 2013). Extensive use of oral contraceptives, tobacco use, and history of having sexually transmitted disease have also been identified as risk factors (Shiffman & Kjaer, 2003).

Age of first sexual intercourse is directly related to the risk of cervical cancer. Women who start their sexual life early are more at risk than women who start their sexual life late. Studies reveal that those women who started their sexual life before the age of 16 years were at double risk than those women who started their sexual life after 20 years because the period of their exposure to HPV has been increased for such women (Green et al., 2003; Natphopsuk, Settheetham-Ishida, Sinawat, Pientong, Yuenyao, & Ishida, 2012).

A study by Burk, Kelly and Feldman (1996) also confirm that the younger the woman is at first intercourse, the higher her risk for developing cervical cancer. This is thought to be due to the mutation of metaplastic squamous cells, which become dysplastic as a result of exposure to cancer causing pathogens through early sexual intercourse (Kerr, Manji, Powe et al., 2001). A similar study done among the Polish population by Wezowska et al. (2013) also found that the risk of developing cervical cancer was higher if first sexual intercourse took place before reaching the age of 16 years.

Green et al. (2003), in a systematic review of 19 epidemiological studies on the risk of genital HPV infection and oral contraceptive use, noted that women with single sex partners were at lower risk of cervical cancer than women who have five or more sex partners. The evidence show that squamous cell carcinoma and adenocarcinoma of the cervix both are associated with the number of sex partners. Wezowska et al. (2013) assess the risk factors for cervical cancer and the occurrence of particular types of HPV among young women in the Polish population identified the number of sexual partners as a risk factor.

There have been studies on the association of sexual behavioural practices with the development of cervical cancer (Schiff & Becker, 2000; Rostad, Schei, & Da Costa, 2003; Juarez-Cedillo et al., 2007). In addition to peno-anal intercourse, oral sex, digital–vaginal sex has also been shown to increase the risk of HPV infection (Hernandez et al., 2008).

Male partner sexual behaviour significantly increases the risk, whereas circumcision has been related to reduction in risk of HPV infection (Castellsague, Bosch, & Munoz, 2003). The literature shows that male involvement in education is important as they contribute to the spread of the disease. This is because the continuous exposure of women to HPV through sexual intercourse is a major risk factor among women, as it is not culturally expected of them to say no to sex, especially when they are married. This becomes even more pertinent as condom use may not give full protection against the transfer of HPV infection.

Reproductive Health Behaviours

Research suggest that the number of live births that a woman has is a consistent risk factor for cervical cancer (Juarez-Cedillo, Vallejo, Manuel Fragosoc, Hernandez-Hernandez, Rodrıguez-Perez et al., 2007; Jensen, Schmiedel, Norrild, Frederiksen, Iftner & Kjaer, 2013). American Cancer Society (2007) also explains that the theoretical principle behind this is that some women may have had a higher exposure to HPV. There is also a direct correlation between parity and the risk of the squamous cell carcinoma. More number of fulltime pregnancies is associated with an increased risk of squamous cell carcinoma among the HPV-positive women. However, there is no significant association reported between parity and adenocarcinoma of the cervix (Munoz, Franceschi, Bosetti et al, 2002). Women who had 5-12 children had 2.6-folds increased risk to have cervical cancer than women who had 0-4 children (Paramita, Soewarto, Widodo, & Sumitro, 2010).

Castellsagué et al. (2003) report that due to hormonal changes during pregnancy, the immune response is modulated to HPV. They also report that a high number of full time pregnancies result in maintaining the transformation zone for a long period of time and thus exposure to HPV and other co-factors increase, resulting in a higher risk of cervical cancer (Castellsagué et al., 2003).

Hormonal contraceptive use has been associated with an increase in the risk of cervical cancer, with the greatest effect in women for longer than 10 years. However, there are some data that suggest that this risk decreases when contraceptive used is discontinued (Smith, Green, de Gonzalez et al., 2003). Research suggests that the risk of cervical cancer goes up the longer a woman takes oral contraceptives (OCs), but the risk reduces again after the OCs use is discontinued. In one study, the risk of cervical cancer was doubled in women who took birth control pills longer than 5 years, but the risk returned to normal 10 years after they stopped (American Cancer Society, 2010).

A comparison of women between high and low income countries who used combined oral contraception for ten years from the age of 20 years showed that the cumulative incidence per 1000 women at the age of 50 years was more in low income countries than in developed high income countries.

The incidence in low-income countries was almost two-fold more than that of high-income countries (International Collaboration of Epidemiological Studies of Cervical Cancer, Appleby, Beral, Berrington de González, Colin, Franceschi, Goodhill, Green, Peto, Plummer, & Sweetland, 2007).

Reproductive practices including inserting of fingers (IARC, 2012; Bosch & Iftner, 2005), tampons, and non-penetrative intercourse has been associated with juvenile respiratory papilomatosis (Bosch & Iftner, 2005) and horizontal transmission of low-risk HPV to the vulva and vagina. Reproductive health behaviours, including contraceptive use, could further expose women to HPV and become risk factors that could lead to cervical cancer. It is important, therefore, that women are educated on such risk factors.

Lifestyle Risk Factors

Two lifestyle factors, smoking and alcohol, use has been reported as risk factors of cervical cancer. Among HPV-positive women, an increased risk of cervical cancer was demonstrated among smokers than non-smokers (Plummer, 2003; Alam, Conway, Chen, & Meyers, 2008; Kapeu et al., 2009). An increased risk of cervical cancer associated with tobacco smoking has been found in many studies (Haverkos, Soon, Steckley, & Pickworth, 2003; Settheetham-Ishida, Kanjanavirojkul, Kularbkaew, & Ishida, 2004; Garland Brotherton, & Condon, 2011; Yetimalar, Kasap, Cukurova et al., 2011).

Cigarette smoking (even passive smoke) has been linked to an increased risk of cervical cancer. Reports on the presence of cigarette carcinogen in cervical mucus, has been described as a possible explanation for the epidemiologic association (Settheetham-Ishida et al., 2004; Garland et al., 2011; Yetimalar et al., 2011). There are, however, some conflicting data with regards to the association between smoking and cervical cancer in southern European populations (Matos et al., 2005). These contradictory results could be attributed to differences in the characteristics of the smoking habit (that is, the amount of tobacco smoked and the number of years as a smoker).

Another study conducted among smoking women who have minor-grade lesions revealed that smoking cessation had beneficial effects on early cervical abnormalities. The study indicated that there was a significant correlation between the extent to which smoking was reduced and the size of the lesion. This suggests the possible role of smoking and HPV carcinogenesis (Castellsague & Munoz, 2003).

A study by Weiderpass, Ye, Tamimi et al. (2001) also concluded that alcoholic women are at high risk for in situ and invasive cervical cancer and for cancer of the vagina. Women who smoke and drink alcohol have deficiency in vitamins A and C and when infected with other sexually transmitted infections are more likely to develop cervical dysplasia or invasive cancer (Schiff & Becker, 2000). Smoking and alcoholism are not practices that are usually associated with women. Women indulging in such practices are therefore likely to hide them. It is important that women are educated on the need to avoid such behaviours to prevent cervical cancer.

HIV Status

Research suggests that the immune system is important in destroying cancer cells and slowing their growth and spread (American Cancer Society, 2013). Women with weak immune systems are at increased risk of cancer. For example, Immuno-suppression: Human immunodeficiency virus (HIV)–the virus that causes AIDS – damages the body's immune system and places women at higher risk of HPV infections. This may explain the increased risk of cervical cancer for women with AIDS (American Cancer Society, 2013). In women with HIV, a cervical pre-cancer might develop into an invasive cancer faster than it normally would.

Another group of women at risk of cervical cancer are those receiving drugs to suppress their immune response. For instance, women being treated for an autoimmune disease (in which the immune system sees the body's own tissues as foreign and attacks them, as it would a germ or those who have had an organ transplant) are at higher risk of cervical cancer (American Cancer Society, 2010). Chlamydia trachomatis and herpes simplex virus are considered cofactors in HPV associated neoplasia. Chlamydia causes cancer through inflammation of the cervix and reduces resistance among HPV-positive women (Castle, & Giuliano, 2003; Smith, Muñoz, Herrero et al., 2002).

Since women who are living with HIV are more susceptible to HPV infection because of the breakdown of their immune system, it is important that this group of women are given more attention and encouraged to go for screening at regular times.

Classification and Stages of Cervical Cancer

According to the American Joint Committee on Cancer [AJCC] (2009), cervical cancer occurs when abnormal cells on the cervix grow out of control. Cervical cancer, like any other cancers, develops in stages. These stages are stages I, II, III and IV (Sobin & Wittekind, 2002; AJCC, 2009; Pecorelli, 2009). The stages are assigned based on the size of the cancer, how deeply the cancer has invaded the tissues surrounding the cervix and whether there are signs of cancer in the vagina, pelvis, or local lymph nodes as well as signs of cancer spread to other organs (AJCC, 2009; American Cancer Society, 2013).

The stages are described using Roman numerals I to IV. Some stages are further divided into sub-stages indicated by capital letters and Arabic numerals (AJCC, 2010). Stage zero or carcinoma *in situ* (CIS) means that there are cancerous cells in the cervix area and that the cells have not spread or grown into the deep part of the cervix (American Cancer Society, 2013). That is, the cancerous cells have not left the area where they started to grow.

At stage I, the cancer is strictly confined to the cervix, and does not extend to the uterine corpus or anywhere else in the body. At this stage, the cancer can be treated. The stage I is further divided into Stages IA, IA1, IA2, IB, IB1 and IB2 (Sobin & Wittekind, 2002; AJCC, 2009; Pecorelli, Zigliani, & Odicino, 2009). For Stage IA, invasive cancer is only identified microscopically and the invasion of the stroma is limited to a maximum depth of 5 mm and no wider than 7 mm while for Stage IA1, the measured invasion of the stroma is not greater than 3 mm in depth and not wider than 7 mm diameter, and for Stage IA2, the measured invasion of the stroma is greater than 3 mm but not greater than 5 mm in depth and not wider than 7 mm in diameter.

In terms of Stage IB, clinical lesions are confined to the cervix or preclinical lesions are greater than Stage IA. Hence, all gross lesions even with superficial invasions are Stage IB cancers. At Stage IB1, the clinical lesions are not greater than 4 cm in size while at Stage IB2, the clinical lesions are greater than 4 cm in size (Sobin & Wittekind, 2002; AJCC, 2009; Pecorelli, 2009; Pecorelli et al., 2009).

In Stage II, the cancer extends beyond the cervix, but does not extend into the pelvic wall. Also, the cancer involves the vagina, but not as far as the lower third. The cancer can still be treated at this stage. Stage II is also further divided into IIA, IIA1, IIA2 and IIB size (AJCC, 2009). At Stage IIA, tumor is without parametrial invasion, while at Stage IIA1, clinically visible lesions are 4.0 cm or less in greatest dimension and at Stage IIA2, clinically visible lesions are more than 4.0 cm in greatest dimension. At Stage IIB, there is obvious parametrial involvement, but not into the pelvic sidewall (Sobin & Wittekind, 2002; AJCC, 2009; Pecorelli, 2009).

When the disease reaches Stage III, it has extended to the pelvic wall and/or involves lower third of the vagina and/or causes hydronephrosis (non-functioning kidney). As such, there is no cancer–free space between the cancer and the pelvic wall (Sobin & Wittekind, 2002; AJCC, 2009; Pecorelli, 2009). The Stage III is also sub-divided into IIIA and IIIB. At Stage IIIA, cancer involves lower third of vagina, but there is no extension to pelvic wall while at Stage IIIB, cancer extends to pelvic wall and/or causes non-functioning kidney (hydronephrosis) (Sobin & Wittekind, 2002; AJCC, 2009).

In Stage IV, the cancer has advanced and spread into many other organs around the cervix and extended beyond the true pelvis or has clinically involved the mucosa of the bladder and/or rectum. This stage is further divided into two: IVA and IVB. At Stage IVA, spread of the cancer goes into adjacent pelvic organs while at Stage IVB, spread of the cancer goes to distant organs (Sobin & Wittekind, 2002; AJCC, 2009).

All these stages in the development of cervical cancer are mainly based on the results of physical examination, which includes a complete pelvic (internal) examination of the cervix, uterus, and ovaries. Patients may also be asked to undergo chest x-ray or bone x-rays to detect whether the cancer has spread outside or distant to the pelvis (American Cancer Society, 2013). Since cervical cancer has a number of different stages of development, health officers need to take advantage of the opportunity to educate women to undertake screening regularly for early detection at the initial stage of the disease.

Cervical Cancer Screening

According to Saslow, Solomon, Lawson et al. (2012), cervical cancer screening should begin at age 21. Thus, women aged less than 21 should not be screened regardless of the age of sexual initiation or other behaviour-related risk factors. According to the 2013 WHO guidelines, by age 30, women are expected to screen at least every three (3) years until age 70. At age 70, testing can be discontinued if the previous three (3) consecutive tests were normal and no abnormal results were reported within the previous ten years (WHO, 2013). This recommendation, if followed, allows for early detection, early start of treatment and prevention of the advancement of the disease.

Over the past 50 years, cervical cancer screening has been effective in reducing morbidity and mortality in high-income countries in contrast to the situation in low-income countries, where effective cervical cancer screening programmes are virtually absent (Franco & Harper, 2005). The highest burden and mortality associated with cervical cancer worldwide is in sub-Saharan

Africa, where a woman has only a 21 percent chance of surviving (Okonofua, 2007).

The Ministry of Health, Ghana and Johns Hopkins Programme for International Education in Gynecology and Obstetrics (JHPIEGO) introduced cervical cancer screening and testing in Ghana in 2001 (MOH, 2011). In 2004, the MOH officially incorporated cervical cancer screening into its National Reproductive Health Service Delivery Guidelines (JHPIEGO, 2008). As part of this policy, HPV vaccine and HPV DNA testing were licensed for use in public hospitals (WHO, 2008). The Pap test and Visual Inspection with Acetic Acid (VIA) were the cervical cancer screening methods approved by the Ministry of Health, Ghana (Odoi-Agyako, 2003; Blumenthal et al., 2007). Cervical cancer prevention is, however, not commonly promoted and a few women screen while infected women do not seek treatment (WHO, 2008; Williams & Amoateng, 2012).

Ghana does not have a national cervical cancer-screening programme (MOH, 2011). In the absence of a national screening programme, most of the cervical cancer screening that takes place in the country can be described as opportunistic screening, where doctors request Pap smears or VIA for patients who are seen in clinics for either general medical examinations or for consultations unrelated to cervical cancer (Adanu et al., 2010).

Countries burdened with high cervical cancer rates in the early-to-mid 20th century adopted national cervical cancer screening programmes, using Pap smear, VIA or HPV DNA test. The Pap smear detects pre-cancerous processes in the endocervical canal of the female reproductive system, whilst the VIA identifies colour changes on the cervix. The HPV DNA test is considered the best and easiest method of screening (Berer, 2008). These programmes led to early detection and treatment of pre-cancerous diseases of the cervix. It consequently reduced the incidence of cervical cancer because detected lesions no longer progressed to cervical cancer (Berer, 2008).

Visual inspection with acetic acid (VIA) has been available in the country since 2001. Even though there has been some public education on cervical cancer, there is still very low rate of patronage of screening services (Chen, Duda, Hill et al., 2005; Duda, Chen, Hill et al., 2005). The few cervical cancer screening programmes available are mostly urban-based with services provided at major hospitals, especially the teaching hospitals. The only hospital providing screening services in a rural setting is the Catholic Hospital in Battor, Volta Region (Christian Health Association of Ghana [CHAG], 2012).

Pap Smear

The Pap test is the main screening test for cervical cancer and pre-cancerous changes. A pap smear is a quick, painless test used to detect early cell changes in the neck of the womb, which may later progress to cancer. Although the Pap test has been more successful than any other screening test in preventing a cancer, it is not perfect. One of the limitations of the Pap test is that it needs to be examined by humans, so an accurate analysis of the hundreds of thousands of cells in each sample is not always possible. Screening efforts have relied largely on Papanicolaou (Pap) smears to detect abnormal cell changes at the cervical transition zone (Juneja, Sehgal, Sharma, & Pandey, 2007; Denny et al., 2010).

The Pap smear test became the standard for early detection of cervical cancer lesions from the 1950s (Tota, Ramana–Kumar, El-Khatib, & Franco, 2014). Pap smear tests are excellent screening tools for pre-invasive cancer. For low income countries, widespread utilisation of the Pap smear test could present a number of challenges. These challenges have led to the use of Visual Inspection with Acetic Acid (VIA).

Visual Inspection with Acetic Acid (VIA)

Gaffikin (2007) and Sankaranarayanan (2007) have demonstrated that visual inspection with acetic acid (VIA), as an alternative sensitive screening method, is cheap and non-invasive and can be conducted in a low-level health facility such as a health centre (Blumenthal, 2003). VIA provides instant results, and those eligible for treatment can receive treatment using cryotherapy on the same day and in the same health facility. This “see and treat” method ensures adherence to treatment soon after diagnosis, hence stemming the problem of failing to honour patient referrals (Blumenthal, 2004: Corneli, Kleine, Salvador-Davila, Gaffikin, Lewis, & Adu-Amankwa, 2004; Sellors, 2003).

A limitation of VIA, however, is that, results are highly dependent on the accuracy of an individual's interpretation. Despite its limited specificity, it is economical, requires little equipment, and provides immediate results (Denny et al., 2010; Jeronimo, Morales, Horna et al., 2005). Both the Pap smear and VIA screening are effective in detecting CIN grade 2-3 (Jeronimo et al., 2005).

HPV Testing

A human papillomavirus (HPV) test is done to find a high-risk HPV infection in women. This test will identify whether a high-risk type of HPV is present. In women, high-risk types of HPV (such as types 16, 18, 31, and 45) cause changes in the cells of the cervix that can be seen as abnormal changes on a Pap test (WebMD, 2015). The use of the HPV test, on its own or in combination with VIA, has the potential to improve cervical cancer screening in low-resource settings (WebMD, 2015).

However, it is expensive and requires infrastructure for processing, and has a long period of waiting for results. It has a higher sensitivity than VIA (90.2%vs.41.4%), but a lower specificity than VIA (84.2%vs.94.5%) (Sankaranarayanan, Nene, Shastri et al., 2009). However, HPV testing is superior to VIA or pap smears because it detects a large number of high-risk sub-types of HPV. This indicates that rapid results for HPV testing may be suitable for performing screening and treatment in low resource settings.

The American Cancer Society (2013) has provided guidelines for early detection of pre-cancers. The goal of the guideline is to provide screening and vaccination recommendation for women. They suggest that all women should begin cervical cancer testing (screening) at age 21. Women aged 21 to 29 should have a Pap test every 3 years. HPV testing should not be used for screening in this age group (could be part of follow-up for an abnormal Pap test). Beginning at age 30, the preferred way to screen is with a Pap test combined with an HPV test every 5 years. This is called co-testing and should continue until age 65. Women aged 30 to 65 should get tested every 3 years with just the Pap test.

The guidelines recommend that among women who are at high risk of cervical cancer because of a suppressed immune system (for example from HIV infection, organ transplant, or long term steroid use) or because they were exposed to DES (Diethylstilbestrol), in utero may need to be screened more often and follow the recommendations of their health care team. The guidelines recommend that, women over 65 years of age who have had regular screening in the previous 10 years without any serious pre-cancers (like CIN2 or CIN3) found in the last 20 years (CIN stands for cervical intraepithelial neoplasia), can stop screening. However, women with a history of CIN2 or CIN3 should continue testing for at least 20 years after the abnormality was found.

Also, women who have had a total hysterectomy (removal of the uterus and cervix) should stop screening (such as Pap tests and HPV tests), unless the hysterectomy was done as a treatment for cervical pre-cancer (or cancer). Women who have had a hysterectomy without removal of the cervix (called a *supra-cervical hysterectomy*) should continue cervical cancer screening. The association notes that in cases where women have been vaccinated against HPV, they should still be screened.

The recommendations of the Society reflect in the various cancer strategies in Ghana. Perhaps, the difference may be that while these recommendations have been implemented in high-income countries resulting into significant reduction in deaths, lack of political will and resources may have prevented the implementation of the recommendations in Ghana. It is equally important to note that there are several methods for testing for cervical cancer with each having its weaknesses and strengths. This must be noted in deciding the best method to use in testing for the disease among women in terms of cost, reliability, convenience and availability.

Cervical Cancer Treatment

Different types of treatment are available for patients with cervical cancer. Some treatments are standard (the currently used treatment), and some are being tested in clinical trials (National Cancer Institute, 2013). The treatment for cervical cancer depends on the disease stage and the patient's age. Fertility–sparing treatment may be offered to the young patient who is keen to have children. The treatment offered to a patient may involve three standard types including surgery, chemotherapy and radiotherapy, or a combination of all three (Jefferies, 2008).

Surgery

Surgery (removing the cancer in an operation) is sometimes used to treat cervical cancer. The following key surgical procedures may be used: Conisation or Cone biopsy, Total hysterectomy, Radical hysterectomy, Radical Trachelectomy, Bilateral salpingo-oophorectomy, Pelvic exenteration, Cryosurgery, Laser surgery and Loop electrosurgical excision procedure (LEEP) (National Cancer Institute, 2013).

Conisation/Cone biopsy is the surgical removal of a cone-shaped segment of the cervix, ectocervical and endocervical tissues. Conisation may be used to diagnose or treat a cervical condition. This procedure is also called a cone biopsy (Harris et al., 2006).

Total hysterectomy is a procedure that removes the uterus or womb including the cervix. There are three approaches depending on different routes of access in performing hysterectomy. If the uterus and cervix are taken out through the vagina, the operation is called a vaginal hysterectomy. If the uterus and cervix are taken out through a large incision (cut) in the abdomen, the operation is called a total abdominal hysterectomy. If the uterus and cervix are taken out through a small incision in the abdomen using a laparoscope, the operation is called a total laparoscopic hysterectomy (National Cancer Institute, 2013).

In a radical hysterectomy or Wertheim's hysterectomy, the whole uterus is removed together with the upper third of the vagina, parametria and the pelvic lymph nodes with or without the para-aortic nodes. Nearby lymph nodes may also be removed. In this type of surgery, not as many tissues and/or organs are removed (National Cancer Institute, 2013).

Radical trachelectomy involves removing the cervix, together with the top 2-3cms of the vagina and joining the top of the vagina to the lower segment of the uterus. This surgery is used in an attempt to preserve fertility (Jefferies, 2008). Radical trachelectomy may be performed either abdominally, vaginally, laparosocpically, or robotically. The feasibility and safety of some of these techniques have been well established, whereas for others the oncological data on outcome are only preliminary (Zakashansky, Bradley, Chuang, 2009).

Bilateral salpingo-oophorectomy is a surgery to remove both ovaries and fallopian tubes (National Cancer Institute, 2013). Here, doctors use a thin, lighted camera and small surgical tool placed through a small (1/2

The guidelines recommend that among women who are at high risk of cervical cancer because of a suppressed immune system (for example from HIV infection, organ transplant, or long term steroid use) or because they were exposed to DES (Diethylstilbestrol), in utero may need to be screened more often and follow the recommendations of their health care team. The guidelines recommend that, women over 65 years of age who have had regular screening in the previous 10 years without any serious pre-cancers (like CIN2 or CIN3) found in the last 20 years (CIN stands for cervical intraepithelial neoplasia), can stop screening. However, women with a history of CIN2 or CIN3 should continue testing for at least 20 years after the abnormality was found.

Also, women who have had a total hysterectomy (removal of the uterus and cervix) should stop screening (such as Pap tests and HPV tests), unless the hysterectomy was done as a treatment for cervical pre-cancer (or cancer). Women who have had a hysterectomy without removal of the cervix (called a *supra-cervical hysterectomy*) should continue cervical cancer screening. The association notes that in cases where women have been vaccinated against HPV, they should still be screened.

The recommendations of the Society reflect in the various cancer strategies in Ghana. Perhaps, the difference may be that while these recommendations have been implemented in high-income countries resulting into significant reduction in deaths, lack of political will and resources may have prevented the implementation of the recommendations in Ghana. It is equally important to note that there are several methods for testing for cervical cancer with each having its weaknesses and strengths. This must be noted in deciding the best method to use in testing for the disease among women in terms of cost, reliability, convenience and availability.

Cervical Cancer Treatment

Different types of treatment are available for patients with cervical cancer. Some treatments are standard (the currently used treatment), and some are being tested in clinical trials (National Cancer Institute, 2013). The treatment for cervical cancer depends on the disease stage and the patient's age. Fertility–sparing treatment may be offered to the young patient who is keen to have children. The treatment offered to a patient may involve three standard types including surgery, chemotherapy and radiotherapy, or a combination of all three (Jefferies, 2008).

Surgery

Surgery (removing the cancer in an operation) is sometimes used to treat cervical cancer. The following key surgical procedures may be used: Conisation or Cone biopsy, Total hysterectomy, Radical hysterectomy, Radical Trachelectomy, Bilateral salpingo-oophorectomy, Pelvic exenteration, Cryosurgery, Laser surgery and Loop electrosurgical excision procedure (LEEP) (National Cancer Institute, 2013).

Conisation/Cone biopsy is the surgical removal of a cone-shaped segment of the cervix, ectocervical and endocervical tissues. Conisation may be used to diagnose or treat a cervical condition. This procedure is also called a cone biopsy (Harris et al., 2006).

Total hysterectomy is a procedure that removes the uterus or womb including the cervix. There are three approaches depending on different routes of access in performing hysterectomy. If the uterus and cervix are taken out through the vagina, the operation is called a vaginal hysterectomy. If the uterus and cervix are taken out through a large incision (cut) in the abdomen, the operation is called a total abdominal hysterectomy. If the uterus and cervix are taken out through a small incision in the abdomen using a laparoscope, the operation is called a total laparoscopic hysterectomy (National Cancer Institute, 2013).

In a radical hysterectomy or Wertheim's hysterectomy, the whole uterus is removed together with the upper third of the vagina, parametria and the pelvic lymph nodes with or without the para-aortic nodes. Nearby lymph nodes may also be removed. In this type of surgery, not as many tissues and/or organs are removed (National Cancer Institute, 2013).

Radical trachelectomy involves removing the cervix, together with the top 2-3cms of the vagina and joining the top of the vagina to the lower segment of the uterus. This surgery is used in an attempt to preserve fertility (Jefferies, 2008). Radical trachelectomy may be performed either abdominally, vaginally, laparosocpically, or robotically. The feasibility and safety of some of these techniques have been well established, whereas for others the oncological data on outcome are only preliminary (Zakashansky, Bradley, Chuang, 2009).

Bilateral salpingo-oophorectomy is a surgery to remove both ovaries and fallopian tubes (National Cancer Institute, 2013). Here, doctors use a thin, lighted camera and small surgical tool placed through a small (1/2 inch) incision usually in the belly button, to remove both ovaries and fallopian tubes (Crimando, 2011).

Pelvic exenteration is a procedure to remove the lower colon, rectum, and bladder. In women, the cervix, vagina, ovaries, and nearby lymph nodes are also removed. Artificial openings (stomata) are made for urine and stool to flow from the body to a collection bag. Plastic surgery may be needed to make an artificial vagina after this operation (Nguyen, McGregor, Freites, Carr, Beynon et al., 2005; Ferenschild, Vermaas, Verhoef et al., 2009; Schneider, Köhler, & Erdemoglu, 2009; National Cancer Institute, 2013).

Pelvic exenterations are classified into five groups: anterior pelvic exenterations, which, in addition to the resection of central pelvic organs, include removal of the bladder and distal urethras bilaterally; posterior pelvic exenteration (PPE), which involves removal of the central organs together with the rectosigmoid (with or without the anal canal); total pelvic exenterations, a combination of both anterior and PPEs; extended exenterations, which include abdominosacral resection; individualized approaches, such as rectal excision with concomitant radical prostatectomy with preservation of the bladder (Nguyen, McPhee, Nguyen et al., 2005).

Cryosurgery is a form of treatment that uses an instrument to freeze and destroy abnormal tissue, such as carcinoma in situ. It is used to treat some kinds of cancer and some precancerous or noncancerous conditions, and can be used inside the body and on the skin. This type of treatment is also called cryotherapy. Cryosurgery is used to treat carcinoma in situ of the cervix (stage 0), but not invasive cancer. It has fewer side effects than other types of treatments, and is less expensive and requires shorter recovery times (National Cancer Institute, 2003, American Cancer Society, 2015b).

Laser surgery is a surgical procedure that uses a Laser (Light Amplification by Stimulated Emission of Radiation) beam (a narrow beam of intense light) in place of a knife to make bloodless cuts into tissues and to remove a surface lesion such as a tumour (National Cancer Institute, 2013). Laser surgery is also used to treat carcinoma in situ of the cervix (stage 0). For this reason, it is not used to treat invasive cancer (American Cancer Soceity, 2015): a treatment that uses electrical current passed through a thin wire loop in place of a knife to remove abnormal tissues or cancer (National Cancer Institute, 2013).

Radiation Therapy

Radiation therapy is a cancer treatment that uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing (National Cancer Institute, 2013; American Cancer Society, 2015c). There are two types of radiation therapy: external and internal radiation therapy. External radiation therapy uses a machine outside the body to send radiation toward the cancer through what is known as external beam radiotherapy (EBRT), which is used to shrink the central carcinoma and also treat the possible sites of regional metastasis (Monga, 2006). Internal radiation (brachytherapy) is when the source of radiation is sealed within a container called an implant and placed directly into the cervix or vagina to treat the cancer and the area close by (Hartmann & Loprinzi, 2005; Cancer Research UK, 2015).

Chemotherapy

Chemotherapy is a cancer treatment procedure that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing (National Cancer Institute, 2013). These drugs are injected into a vein or given oraaly which enter the bloodstream and can reach all areas of the body, making this treatment useful for killing cancer cells in most parts of the body. Chemotherapy is often given in cycles, with each period of treatment followed by a recovery period (American Cancer society, 2015d). Combination chemotherapy is where the mechanism of different drugs complement each other to produce maximal cell kill-synergy (Nattress, 2008). It is difficult to accept that in spite of the numerous options for the treatment for cervical cancer, women are still dying of the disease. The treatment options need to be promoted and made available and affordable for cervical cancer patient who still have the chance to survive.

Cervical Cancer Stages and Type of Treatment

The treatment option for cervical cancer mainly depends on the disease's stage and the patient's age (National Cancer Institute, 2015). The exact location of the cancer within the cervix, the type of cancer (squamous cell or adenocarcinoma), age, overall physical condition, and whether a patient will want to have children are also considered when deciding on type of treatment (American Cancer society, 2015e).

Stage 0 (Carcinoma in situ)

Although the AJCC staging system classifies carcinoma in situ (CIS) as the earliest form of cancer, doctors often think of it as a pre-cancer because the cancer cells in CIS are only in the surface layer of the cervix. For this stage, patients could be treated through the following treatment options: loop electro-surgical excision procedure, Laser surgery, conisation, cryotherapy, total hysterectomy and internal radiation therapy for patients who cannot have surgery because of co-existing medical conditions (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

Stage I Cervical Cancer

Stage 1A cervical cancer is separated into stage IA1 and IA2. Treatment for stage IA1 may include the following: Conization, Total hysterectomy with or without bilateral salpingo-oophorectomy. Treatment for stage IA2 may include modified radical hysterectomy and removal of lymph nodes, radical tracheletomy as well as internal radiation therapy for women who cannot have surgery (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

Stage IB patients can be treated through a combination of internal and external radiation therapy, radical hysterectomy and removal of lymph nodes followed by radiation therapy plus chemotherapy (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

Stage II Cervical Cancer

This stage is further categorized into two as IIA and IIB. Similar to patients in stage IB, patients in stage IIA can be treated using the following options: a combination of internal and external radiation therapy, radical hysterectomy and removal of lymph nodes or radical hysterectomy and removal of lymph nodes followed by radiation therapy and chemotherapy. The recommended treatment for patients in stage IIB is internal and external radiation therapy combined with chemotherapy (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

Stage III Cervical Cancer

Patients categorised in this stage can be treated through internal and external radiation therapy with concurrent chemotherapy and surgery to remove pelvic lymph nodes followed by radiation therapy with or without chemotherapy. Also, a clinical trial of chemotherapy to shrink the tumour followed by surgery or a clinical trial of chemotherapy and radiation therapy given at the same time, followed by chemotherapy can be recommended for patients at this stage (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

Stage IV Cervical Cancer

Patients diagnosed with stage IV cervical cancer can be broadly divided into two groups IVA and IVB. Recommended treatment for both stages may include internal and external radiation therapy combined with chemotherapy. This treatment is given as palliative therapy to relieve symptoms caused by the cancer and to improve quality of life. Clinical trials of new anti-cancer drugs or drug combinations may also be recommended (National Cancer Institute, 2015; American Cancer Society, 2015e; WebMD, 2015).

The above information shows that each of the numerous stages of the disease has its own treatment method ranging from surgical to chemical methods. Women need to know about the various stages of disease, what their chances are and whether they require a combination of two or more different treatment methods for the effective treatment of the disease.

Knowledge and Perceptions about Cervical Cancer

Knowledge of the disease has been categorised into awareness of cervical cancer itself, knowledge of risk factors, available screening services and treatment options for patients. Knowledge on cervical cancer screening is critical in determining whether a woman will undergo cervical cancer screening in addition to making cancer screening facilities available in the primary health centres (Aswathy, Quereshi, Kurian, & Leelamoni, 2012).

Knowledge and Awareness about Cervical Cancer among Women

Over the past three decades, studies have consistently found high awareness but low knowledge about cervical cancer among women, particularly those from rural settings (William, 2014; Abiodun, Fatungase & Olu-Abiodun, 2014; Amosu, Degun, Babalola, & Thomas, 2011). Research indicates that about 50 percent of individuals have ever heard of the disease, however, they lack knowledge on the risk factors, screening services, symptoms and treatment options (Hoque, Ghuman, Coopoosmay, & Van Hal, 2014; Ndikom & Ofi 2012; Tebue, Major, Rapiti et al., 2008).

Studies have found low knowledge of risk factors of cervical cancer among women over the years and across the world. For example, Aswathy, Quereshi, Kurian & Leelamoni's (2012) study in Kerala, India, revealed that 89.2 percent of the participants did not know any risk factor for cervical cancer. Similar results were reported by Leung and Leung (2010) in a study among Hong Kong Chinese female tertiary students. They observed that 97 per cent of participants lacked knowledge of the risk factors of cervical cancer. In Africa, low levels of knowledge have been reported in Cameroon (Tebeu et al., 2008), Ghana (Adanu, et al., 2010; Williams et al., 2013), Nigeria (Amosu et al., 2011; Abiodun, Fatungase & Olu-Abiodun, 2014) and South Africa (Francis et al., 2011). In their studies Abotchie & Shokar, (2009) and William, Kuffour, Ekuadzi et al (2013) report that less than 8 per cent of women were aware of the link between HPV and cervical cancer in Ghana.

Furthermore, misconceptions about risk factors associated with cervical cancer have been reported among women. In Zambezi province, Mozambique, cervical cancer was thought to be associated with curses placed on the woman (42%) (Audet et al., 2012). In Ghana, participants wrongly reported candidiasis, having abortion, poor eating habits, infertility, alcohol consumption, drug use, wounds from cuts, and excessive amounts of sexual intercourse as risk factors of cervical cancer (William et al., 2013).

Knowledge about cervical cancer screening services as well as where they can be found is quite important in determining the uptake of screening. Findings of studies have shown that there is low knowledge about cervical cancer screening recommendations and services (Ndikon & Ofi, 2012). In a survey among 140 women between ages 20 and 35 in a university in Ghana, Abotchie and Shokar (2009) found that women were unaware of screening recommendations. About 80 per cent of women did not know when a woman should have first screening and 90 per cent did not know the frequency of screening for their age. In 2010, it was reported that 20 per cent of women did not know that screening is recommended for menopausal women (Leung & Leung, 2010).

A study by Al Sairafi and Mohamed (2009) show that only 52.3 percent of women in Kuwait, knew about screening services. A study in Nigeria by Ndikom and Ofi (2012) further observe that more than half of women did not know of the types of cervical cancer screening methods. A study by Wellensiek, Moodley, Moodley and Nkwanyana (2002) on knowledge of cervical cancer screening among women from low, middle and upper social/financial backgrounds revealed that patients were not aware of cervical cancer screening or facilities available for this purpose.

Knowledge of cervical cancer symptoms is very limited among non-cancer patient women. In London, about 60 per cent and 75 per cent of women did not know that vaginal bleeding in-between periods and unusual vaginal discharge were symptoms of cervical cancer (Ezechi, Ostergren, Nwaokorie et al., 2014). Women in Ghana did not know that changes in bowel habits (84%), abnormal bleeding (58%) and unexplained weight loss are symptoms of cervical cancers (William et al., 2013).

Women named schools, churches, communities, primary health providers, or work place as possible sources from which they would expect information. Lack of awareness about what the symptoms or signs of the disease are and the health outcomes could lead to undue anxiety, confusion, or denial (Shulman et al., 2010; Keshavarz et al., 2011; Basu et al., 2006; McFarland, 2003). The literature shows that women have little or no knowledge of cervical cancer in terms of causes, symptoms and risk factors as well as screening and treatment services. This has implication for health seeking behaviour in terms of screening and treatment. This situation can be addressed through intensive education among women. It is only then that women can get the right information on how to avoid getting the disease and the treatment options for those infected.

Knowledge and Awareness of Cervical Cancer among Men

Research shows that men play a significant role in the healthcare decisions of women (Williams & Amoateng, 2012). Men can contribute to reducing cervical cancer burden by protecting their partners from HPV infections, motivating them to be screened or allowing them to protect themselves against the disease (Castellsague et al. 2003; Maree, Wright, & Makua, 2011). Awareness and knowledge of men of the risk factors, screening recommendations and services, and symptoms of cervical cancer are presented in the following paragraphs.

Studies by Maree, Wright and Makua (2011) and Williams & Amoateng (2012) among men indicated that more than half of them had never heard of cervical cancer. In South Africa, none of a 980 sample of men mentioned the HPV as risk factor and 22 per cent believed that men do not contribute to cervical cancer in women (Maree et al., 2011). The participants noted higher risk for having multiple sexual partners among women (74%) compared to multiple partners among men (70%) as a risk factor to a woman.

Fear of stigmatisation (Williams & Amoateng, 2012) could cause men to blame women with cervical cancer for their HPV infection (Fernandez et al. 2009). Findings of a study by Williams and Amoateng (2012) indicate that 30 per cent of the men had no knowledge of the signs and symptoms of the disease. Of those who claimed they knew the symptoms, 16.5 per cent were of the opinion that a wet vagina was a symptom of cervical cancer while 15.9 per cent attributed it to dry vagina.

A study by Pitts et al. (2009) in Singapore showe that only 46 per cent of men had heard of Pap smear test and of those who knew about it, only about 50 per cent were sure of the frequency of screening. The limited knowledge of cervical cancer among men is essentially risky for women since they have limited sexual power and are subservient to men (Denny et al., 2006). This ignorance about the disease could mean that men are not likely to adjust their sexual behaviour to reduce the risk of HPV transmission to women (Pitts, et al. 2009).

The main issue that emerges from the literature is that, like women, a number of men also seem to have little or no knowledge about cervical cancer. This could be attributed to some socio-cultural or gendered norms that seem to make men gatekeepers of women's health seeking behaviour. The fact that men do not have knowledge about the disease may have negative implications for health seeking behaviour for the disease among women Thus, male education on the disease should be part of the cervical cancer prevention strategy.

Barriers to Cervical Cancer Screening and Treatment

Differences in cervical cancer screening and treatment are apparent in various populations and sub-populations (Downs et al., 2008). These differences in screening result in different cervical cancer disease patterns among women worldwide. The barriers to cervical cancer screening and treatment can be classified into individual, interpersonal, community and structural factors (Kelly et al., 2008; Louchini & Beaupré, 2008; Reis, Bebis, Kose et al., 2012; Williams & Amoateng, 2012). For instance, the social environment, cost of health care, gender roles and cultural beliefs and values could determine whether a woman will seek and receive health care services or not (Katz et al., 2007).

Individual Level Barriers to Cervical Cancer Screening and Treatment

Individual level factors include knowledge, psychology and finances. One of the barriers to screening uptake is lack of or low level of knowledge and awareness of cervical cancer screening (Fort et al., 2011; Basu et al., 2006; Paolino & Arrossi, 2011; Parsa et al., 2006; Markovic, Kesic, Topic,& Matejic, 2005; McFarland, 2003; Duran, 2011; Ansink et al., 2008). For instance, Blumenthal et al. (2005) suggest that knowledge of cervical cancer is among the barriers that account for the low rates of screening. Women are unlikely to present themselves for cervical cancer screening with inadequate knowledge. Some Ghanaian women (Adanu, 2002) as well as men have never heard of the disease (Williams & Amoateng, 2012). It appears that after people have been exposed to cervical cancer knowledge they accept to screen (Ezechi et al., 2013).

A study in Nigeria, however, produced different results (Gharoro & Ikeanyi, 2006). In this study, 195 female health workers were interviewed to identify factors that could influence the awareness and utilization of the Pap smear as a screening test for cervical cancer. It was found that knowledge about cervical cancer alone may not be a guarantee for screening service uptake. Instead, it may inadvertently work against screening uptake (Gharoro & Ikeanyi, 2006; Agurto et al., 2006; Lee, Fogg, & Menon, 2008; Sudenga, Rositch, Otieno et al., 2013).

Economic factors, both tangible and intangible cost, act as barriers to women seeking screening services for screening and early diagnosis. For instance, Ebu et al. (2015) in a study in Elmina, Ghana, among 392 women ages 10-74 found that, high cost of Pap smear screening was a barrier to the uptake of cervical cancer screening among the respondents. Even when screening is provided for free through health insurance, some women are not only worried about possible costs for treatment and drugs (Keshavarz et al., 2011; Agurto et al., 2004; Parsa et al., 2006; Smith, Cokkinides, & Eyre, 2006). Also indirect cost, like travelling costs to visit healthcare providers, loss of daily earnings, or missing time for other life priorities or long working hours keep women from participating in screening (Muhamed et al., 2012; Parsa et al., 2006; Basu et al., 2006).

A variety of psychological factors can influence a woman's perception and participation in early detection of cervical cancer. Fear of the screening test itself, the consequences of the screening outcomes, diagnostic procedures and treatment play a major role in prompting women to avoid going in for cervical cancer screening (Agurto et al., 2004; Basu et al.,2006; Parsa et al., 2006). Other factors that consistently emerged in several interview-based studies give reasons for the refusal of women to screen. These include shyness, uneasiness concerning medical examination and feeling ashamed to expose private parts, especially when the screening is done by a man (Keshavarz et al., 2011; Parsa et al., 2006; Ansink et al., 2008).

The refusal of some women to accept that they are at risk of developing cervical cancer was also found to be a barrier to screening. Studies have reported that women do not necessarily distinguish between a screening and diagnostic test and do not attend screening because they do not think they are at risk of developing cancer or that screening can prevent them from developing cancer (Fort et al 2011; Basu et al., 2006; Parsa et al., 2006; Markovic et al., 2005; Duran, 2011). There is evidence that a number of individual level factors constrain women's decision to undergo cervical cancer screening and treatment. Women's lack of knowledge about the disease, financial constraints as well as psychological factors have emerged as the notable barriers at this level. Hence, in addressing the issue of screening uptake, interventions must be targeted at various categories of women at the individual level as well as other levels of influence in decision-making.

Interpersonal Barriers to Cervical Cancer Screening and Treatment

Interpersonal processes and relatives have been reported to affect seeking cervical cancer screening and treatment. For example, in seeking health information and healthcare, a lot of women primarily rely on information and support from their family and friends. This can be done through close interpersonal communication networks, especially in societies where lives are more centred on family, village and social group ties (Muhamed et al., 2012).

Some studies show that lack of social support was a barrier because women do not want to visit screening services on their own, especially when they have to travel over long distances to the place where the screening is provided (Basu et al., 2006). On the other hand, having a male partner who is supportive of cancer screening does help women to decide to take part in such screening (Winkler, Bingham, Coffey, & Handwerker, 2008). Even though social support has been identified in the literature as a motivating factor in women's decision to undergo screening and treatment, there is not much information on the fact that lack of it could constitute a barrier to screening behaviour for the disease. It cannot be denied, however, that lack of social support may have implications for the willingness of women to go for screening and seek treatment for the disease.

Community Barriers to Cervical Cancer Screening and Treatment

The community barriers to cervical cancer screening and treatment include social norms and other socio-cultural factors that constraint the uptake of cervical cancer screening (National Cancer Institute, 2005). Socio-cultural issues among others include gender norms and health and disease beliefs. Gender inequalities and inter-dependence are some of the main barriers that have been observed to prevent women from the uptake of screening. Women who are dependent on their husbands would be less likely to seek cancer screening, diagnosis or treatment on their own (Parsa, Kandiah, Abdul Rahman, & Zulkefli, 2006). Women are reported to find it difficult to convince their partners for financial or emotional support to visit healthcare providers for screening, especially if they are not visibly ill (Keshavarz, Simbar, & Ramezankhani, 2011; Fort, Makin, Siegler et al., 2011; Basu, Sarkar, Mukherjee et al., 2006; Parsa et al., 2006; Bingham, Bishop, Coffey et al., 2003).

Basu et al. (2006) conducted a study in India to determine the social barriers to compliance to cervical cancer screening. A sample size of 500 randomly selected non-compliant and compliant women were interviewed. The study found that though women were willing, they could not attend because of an inability to leave household chores, preoccupation with family problems and lack of approval from their husbands. Finally, cultural taboos regarding women’s health care behaviours were also identified including attitudes towards male doctors examining the “private parts” of visibly healthy women and the lack of the perceived need for preventive care.

Other barriers may also be linked to the cultural practices of the community. These include values about health and illness. Women reported that even if they theoretically understood the possible health benefits of cervical cancer screening and early diagnosis, it was simply not common in their community to visit a healthcare provider, especially when feeling healthy (Keshavarz et al., 2011; Markovic et al., 2005; Duran, 2011). Some had opted to stay away from the programme because they had no symptoms of the disease (Basu et al., 2006).

In studies by Fort et al. (2011) and Chirwa et al (2010), women were reported to be ashamed of being sick and were concerned about being stigmatized or excluded from the community if they presented for gynaecological examinations or were diagnosed with cancer. They were also worried that their partners or community members might not believe them and start doubting their moral standards and social integrity (Downs et al., 2008). The women also felt that they could be stigmatised if they went to seek preventive care and would be socially classified as sick. In areas where HIV is common, women were also afraid that others might think they had HIV if they were diagnosed with cervical cancer. Such behaviours, they felt, could also lead to social isolation and stigmatization (Keshavarz et al., 2011; Markovic et al., 2005; Duran, 2011).

Women are reported to avoid being screened for cancer because they believe the disease is not curable and therefore prefer not to know if they have it (Agurto et al., 2004; Parsa et al., 2006; McFarland, 2003). Women also kept away from participating in screening or treatment because of the belief that surgery could lead to total loss of uterus, further spread of cancer which leads to death, or assumptions that total mastectomy is the only treatment (Ma et al, 2012).

Spiritual explanations of disease causes also prevent women from seeking screening and treatment (Chirwa et al, 2010). Cancers were found to be associated with witchcraft among some women who have the conviction that only traditional healers can heal them (Chirwa et al., 2010). Some women even believe that there was no effective therapy for cancer, especially when all the people they knew had cancer had died (Shulman, Willett, Sievers, & Knaul, 2010). The fact is that every woman lives in a particular community and is affected by the socio-cultural and gendered norms of that community. These norms have been identified as factors that constrain a woman's health seeking behaviour. Some of these barriers could be addressed through intensive education on the disease among community members as a whole.

Structural Barriers to Cervical Cancer Screening and Treatment

Structural factors include local, institutional, state and national policies and laws that regulate actions and practices for disease prevention, control and management. Institutional barriers refer to barriers related to the biomedical health system that can prevent women from accessing screening. These include inadequate public health education and lack of patient-friendly health services (Markovic et al., 2005). For example, poor quality of screening equipment and lack of facilities for screening have been found to be a constraint to screening acceptance among some women (Agurto et al., 2004; Fort et al., 2011).

In some developing countries, primary health centres currently do not have the capacity to provide VIA or visual screening with Lugol's iodine, let alone cytology and HPV testing. Most centres in low-income countries are not equipped with specula, light source, couches, or equipment to sterilize used and soiled instruments (Mahesh, 2013). Furthermore, cervical biopsies or providing cryotherapy is seldom possible in most primary healthcare settings. (Fort et al., 2011; Mahesh, 2013),

The secondary healthcare facilities in developing countries are also poorly equipped to provide screening, diagnosis, and treatment services for cervical cancer precursor lesions. Secondary and tertiary care facilities for treatment of invasive cancer and the means to subsidize or finance healthcare costs associated with diagnosis are inadequately conceived (Winkler, Bingham, Coffey, & Handwerker, 2008). In addition, treatment options are inadequate in many developing countries, leading to a substantial proportion of cancer patients dropping out of screening and treatment (Mahesh, 2013).

However, it has been reported that provision of a cervical cancer screening service is not sufficient to ensure uptake. For instance, in Ghana, VIA is about $5 (Quentin, Adu-sarkodie, Terris-Prestholt, Legood, & Opoku, 2011) and in selected health facilities screening services are free yet cervical cancer screening uptake was still low (Blumenthal et al., 2005; Odoi-Agyarko, 2003). The reason for the low uptake of cervical cancer services in facilities where the services are provided for free has been associated with provider barriers.

Finally, political challenges have also been identified as structural barriers to the uptake of screening. Some developing countries do not have the equipment, trained personnel, or supplies to organise national or even regional screening programmes as a result of political instability, lack of political will and funding (Sankaranaryanan et al., 2009: Sepulveda & Prado, 2005; Murillo, Almonte, Pereira et al., 2008: Nessa, Hussain, Rahman et al., 2010: Khuhaprema et al., 2012). Thus, successful implementation and sustenance of cancer screening require political commitment, regular budget line to support capital and recurring costs (Mahesh, 2013). Healthcare resources are required to improve healthcare infrastructure for identification and invitation of eligible women to screening tests, the evaluation of high-quality screening tests and treatment of those with cancer (Mahesh, 2013).

Structural barriers to cervical cancer screening also emerged in the literature. It is important to note that local and national policies are indispensable when addressing barriers to screening and treatment of cervical cancer. The government needs to initiate intensive education on the disease, decentralising screening services to the district or community level by establishing more screening and treatment facilities and funding the cost of screening and treatment.

Provider Barriers to Cervical Cancer Screening and Treatment

The provider barriers refer to the interpersonal or institutional factors at the health facility level that prevent women from seeking cervical cancer screening and treatment. For example, mistrust of health workers, lack of knowledge of health workers and attitudinal problems of health workers has been reported (Agurto et al., 2004; Fort et al., 2011).

Mistrust of the healthcare providers has been reported in two ways. Firstly, women mistrust the capacity of health workers to perform early detection tests or to interpret the test results (Agurto et al., 2004; Fort et al., 2011). Other reasons women gave for not undergoing early screening services were concerns about privacy during screening and the suspicion that the service providers may not be able to maintain confidentiality of the test results (Agurto et al., 2004; McFarland, 2003; Mutyaba et al., 2006). In some communities, women were concerned about being screened by people they knew or that others would find out about their test results later (Chirwa et al., 2010). The ethnicity and sex of the screening service provider could also prevent women from getting screened (Basu et al., 2006; Ansink et al., 2008).

Human resource considerations are also important to screening and treatment. Firstly, the lack of trained human resources to facilitate the steps between different levels of the screening processes, and continuous monitoring and evaluation using health information systems, serve as barriers to the uptake of screening especially in rural areas (Mahesh, 2013). Secondly, some health workers lack knowledge of cervical cancer.

A study conducted in South Africa from 2005 to 2006 on the route of cervical cancer signs and symptoms to treatment among 15 women with advanced cervical cancer identified that lack of knowledge and awareness among health care professionals resulted in a low suspicion of cancer and misdiagnosis. Based on this result, it was recommended that a national cervical cancer strategy including health education and re-training of health professionals be made a priority (Schalkwyk et al., 2008).

Some women have report attitudinal problems associated with health workers as limiting their update of cervical cancer screening and services. Others perceive that some healthcare providers do not provide early detection tests unless they have symptoms and signs and will refuse to provide screening if the women seem healthy (Markovic et al., 2005). Other major challenges impeding participation in early detection programmes include, the language used by physicians, lack of systematic consideration of a patient's autonomy, failure to respect the privacy of women and their feelings/sensitivities, rude behaviour of nurses, and absence of mechanisms that can provide decision-making power to women (Chirwa et al., 2010).

Integrating cervical cancer early detection efforts into general healthcare services is challenging. It was also observed that access to public and private healthcare services to avail themselves to early detection of gynaecological cancers is a major challenge for many women in low and middle-income countries (Keshavarz et al., 2011; Agurto et al., 2004). Difficulty in navigating through large and complex healthcare facilities can also be a problem (Mahesh, 2013). The ability to provide adequate and affordable access to screening services and physical examination by health workers is a major obstacle in health services in many less developed countries.

The consistent lack of prioritisation, adequate planning, investments and resource allocation over several years, has given rise to the situation (Mahesh, 2013). The literature reinforces the negative attitude of health personnel as a barrier to health seeking behaviour for the disease. These have to do with the way they communicate with patients, how they handle confidential issues and the level of respect for the privacy of patients. This shows that the very people who have been trained to provide health services become barriers to women's willingness to go for screening and treatment for cervical cancer. This is a major issue that should be addressed.

Behavioural Change Communication and Cervical Cancer Screening

Behavioural change communication has been found to be a factor that determines the willingness of women to undergo screening for cervical cancer. A study conducted in 2010 in two rural communities in Mozambique by Audet, Silva Matos, Blevin et al. (2012) found that about 86 per cent of women accepted VIA screening after they were provided information about the disease and offered screening. The uptake at the other clinic was as high as 100 per cent. It was therefore concluded that information about cervical cancer screening was significantly associated with uptake, suggesting that educational campaigns need to be undertaken.

To promote the uptake of screening for early detection of cancer, there must be concerted efforts by people such as cancer patients, survivors, relatives of cancer patients, the general public, and activists to convince politicians and health service administrators to make policy decisions to implement and sustain early detection programmes in public health services. This also provides the opportunity for people to get involved in efforts to rally policymakers and the general public to fight against cancer (Mahesh, 2013). Even though behavioural change communication is crucial to the promotion of cervical cancer screening behaviour among women, it seems much has not been done in this direction. This has negative implications for screening and treatment among women.

Coping Mechanisms Used by Cervical Cancer Patients

Coping strategies employed could either be problem-focused or emotion-focused and the strategies employed influence adaptation to the diagnosis (Mukwato et al., 2010). Illness experiences and coping mechanisms of psycho-social problems are related to beliefs of disease causation, self-stigmatization and sexuality (Agurto et al., 2004; Fort et al., 2011). Four predominant coping mechanisms have been reported in the literature for the patients and family. These include seeking social support, reliance on God, positive suggestion/attitude or re-affirmation and acquisition of health education (Mukwato et al., 2010).

Positive coping means a good quality of life, which will contribute significantly to improvement in the prognosis. In low resource settings, medical teams and patient families are unable to provide psychological and emotional support throughout the fight against the disease. A study in India by Ramanakumar, Balakrishna and Ramarao (2005) found that positive thinking, sense of purpose in life and strong family support were the coping mechanisms used by respondents in achieving completion of treatment and prolonging their lives. Besides, regular health seeking behaviour, general medication and emotional support from friends and family members were revealed to be very important coping mechanisms for respondents.

Furthermore, Ratanasiri, Boonmongkon, Upayokin et al. (2000) conducted a qualitative study to determine the health seeking behaviour and illness beliefs as well as coping mechanisms used by cervical cancer patients. The study found that support from husbands, family and the community were the coping mechanisms used in managing the problems faced by cervical cancer patients. The coping mechanisms were also believed to be shaped by the level of stigmatisation attached to the illness in terms of sexual relationships with their husbands, beliefs in the meaning and causation of cervical cancer, as well as the health care system being utilized (Ratanasiri et al., 2000).

There is no doubt that chronic diseases are stressful and patients need to adopt various methods to cope with their conditions. From the literature, a number of coping mechanisms have been identified. However, it appears that little information is available on why some patients would select some mechanisms over the others. In the absence of palliative care in Ghana, social support, belief in God and positive attitude may be some of the reasons why some cervical cancer patients have survived so far.

Male Support for Cervical Cancer Screening and Treatment

Male support for female partners during cervical cancer screening and treatment is paramount in reducing cervical cancer fatalities. Yet, this has been scarce in the literature and the few extant literature fail to specify the specific supports provided by males for their female partners during screening and treatment of the disease. Research suggests that men are willing to support their female partners in cancer screening and treatment activities (Trevino et al., 2012; Thiel de Bocanegra et al., 2009). However, most men do lack knowledge of cervical cancer and their partners' health histories. The implication is that cervical cancer education is urgently needed, and education efforts may include male community members, especially as the males perceive themselves as responsible for the financial burden of care.

Williams and Amoateng (2012) undertook a qualitative study with Ghanaian men in Kumasi on male involvement in cervical cancer screening. In the study, the participants indicated that they would be willing to provide spousal support for cervical cancer screening if they knew more about the disease and the screening methods. Williams and Amoateng (2012) conclude that cervical cancer education interventions targeting Ghanaian men need to correct misconceptions and increase spousal support for cervical cancer screening. This is because men play an important role in the health seeking behaviours of Ghanaian women.

However, these studies did not specify whether male partners were willing to provide financial, social or emotional support to their female partners. Even though male support for cervical cancer patients is crucial for spouses' chances of survival, literature in this area is scarce. It appears that men have not been targeted because cervical cancer is a women's disease. Since the disease is sexually related, it is important that men are also educated on the causes, prevention and treatment.

Summary

This chapter provided a comprehensive review of literature on the epidemiology of the disease from the global to the local perspective. It drew on the incidences, prevalence as well as the mortalities resulting from the disease worldwide, which make it one of the crucial diseases among women that must be approached with a sense of urgency. It also enlightened on the nature of the disease in terms of its cause, symptoms, risk factors as well as the various stages of its development and their specific appropriate treatments. It therefore concluded that the disease is not only prevalent and deadly, but it is also a complicated disease that is expensive to treat.

In this chapter, the knowledge and perceptions of both men and women about the disease were brought to light, and this has helped to unearth the knowledge gap on the disease among people in terms of gender. Different types of barriers to the uptake of screening and treatment at various levels were also examined in the literature. These explain why many women, particularly those from the developing world, may not screen for the disease or go for treatment. Strategies adopted by cervical cancer patients to cope with the disease and the roles played by male partners in supporting the patients were also captured in the literature. In a nutshell, the chapter provided adequate information about cervical cancer in all spheres.

CHAPTER THREE

MODELS ON HEALTH SEEKING BEHAVIOUR

Introduction

Over the years, psychologists have been concerned with attributes that motivate choices that affect health-seeking behaviour (Nutbeam & Harris, 2004). Among the psychological theories and models that have been applied in research dealing with cervical cancer screening and treatment are the "Theory of Reasoned Action" (Ajzen & Fishbein, 1980), the "Theory of Planned Behaviour" (Ajzen & Fishbein, 1980; Ajzen, 1991), "The Concept of Biographical Disruption" (Bury, 1982), the "Health Belief Model" (Rosenstock, 1960; Rosenstock, Strecher, & Becker, 1988) and the "Socio-ecological model" (McLeroy, Bibeau, Steckler, & Glanz 1988).

Theory of Reasoned Action

The Theory of Reasoned Action (TRA) suggests that behaviour is influenced by beliefs, attitudes and intention (Figure 2). It argues that behavioural intention is the most important determinant of behaviour (Ajzen & Fishbein, 1980; National Cancer Institute, 2013). This is illustrated in figure 2 below. It identifies two major factors that contribute to such intentions (Ajzen & Fishbein, 1980; Coffman, 2002): (1) a person's attitude toward the behaviour – attitudes can be defined as positive or negative emotions or feelings toward behaviour, a person, a concept, or an idea; (2) a person's subjective norms about the behaviour. In the TRA, subjective norms are defined as the opinions or judgments, positive or negative that loved ones, friends, family, colleagues, professional organisations, or other key influential people may have about a potential behaviour.

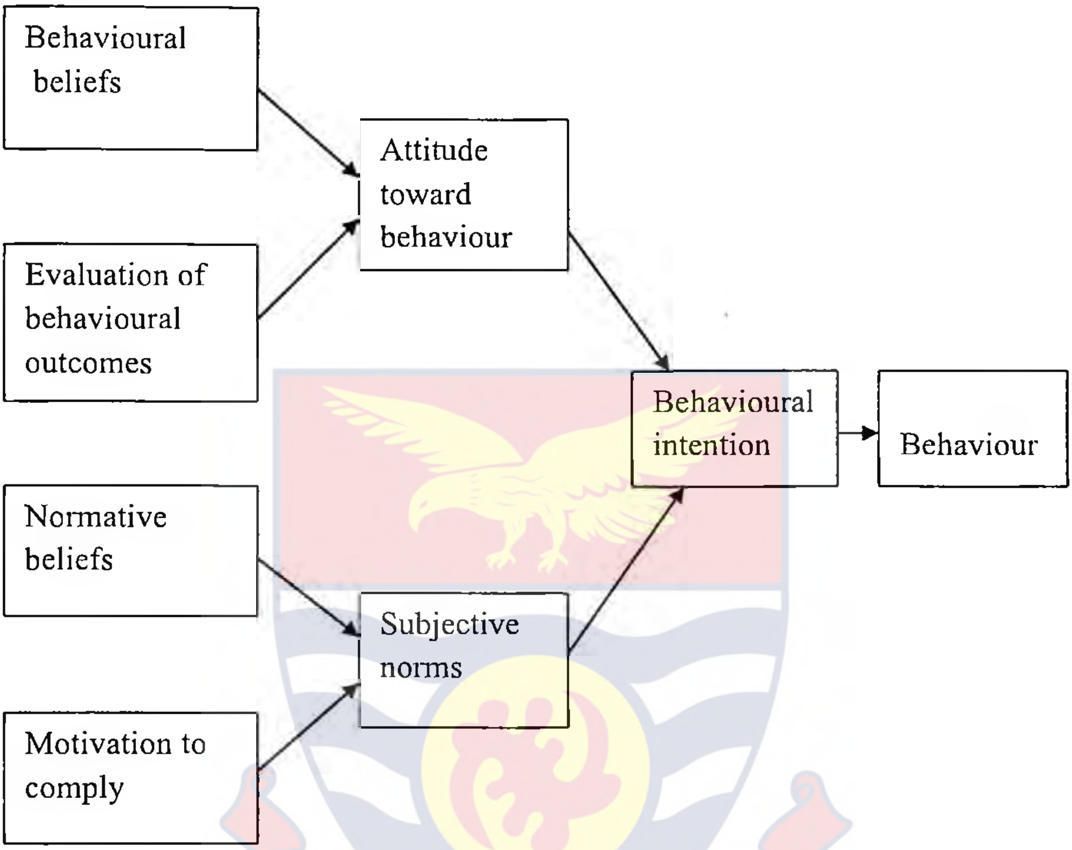


Figure 2: Theory of Reasoned Action

Source: Ajzen & Fishbein (1980)

Under the TRA, attitudes toward a specific behaviour are seen as a function of the person's beliefs about the consequences of such behaviour. TRA assumes that all other factors (including culture and environment) will affect behaviour only through behavioural intentions and subjective norms (Montano & Kasprzyk, 2008). For instance, smoking marijuana may have a negative impact on a person's concentration and work performance. These are called *behavioural beliefs* (Ajzen & Fishbein, 1980). The theory is an individual level theory that does not take into account other external influencing factors (National Cancer Institute, 2013).

Subjective norms are influenced by *normative beliefs,* which refer to whether a person may think his/her significant other will approve or disapprove of his or her behaviour. Another component of normative beliefs is the person's motivation to comply with other people's ideas and potential approval (Coffman, 2002). In simple terms, the main TRA assumption is that people will engage in a behaviour when they have a high intention, and their intention is increased when they evaluate a behaviour positively (attitude) and believe that significant others want them to engage in (subjective norm) (Downs & Hausenblas, 2005).

TRA is currently one of the most influential theories in behavioural change communication and is frequently used also in programme evaluation (Coffman, 2002). Even though the TRA is able to predict a variety of behaviours, it was developed to explain only volitional behaviours (i.e. personal power to engage in the behaviour) (Fishbein & Ajzen, 1975).

Therefore, it is important to maintain some caution in concluding that the intention of adopting certain behaviour always translates into actual behavioural performance (Schiavo, 2007). Since the TRA does not account for non-volitional behaviours (i.e. less able to make a choice to engage in the behaviour), the theory was later expanded to include *perceived behavioural control*, thus forming the Theory of Planned Behaviour (TPB) (Ajzen, 1988, 1991). This is discussed further in the section under the Theory of Planned Behaviour.

Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB) is an extension of the Theory of Reasoned Action (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). It seeks to address the limitations of the original model in dealing with behaviours over which people have incomplete volitional control (Ajzen, 1991). Ajzen and colleagues proposed the TPB to predict behaviours over which people have incomplete volitional control (Ajzen, 1991; Ajzen & Driver, 1991; Ajzen & Madden, 1986). The theory adds *perceived behaviour control* to the TRA to account for factors outside of the individual's control that may affect his or her intention and behaviour (Figure 3). This was partly based on the idea that behavioural performance is jointly determined by motivation (intention) and ability (behavioural control).

Ajzen (1991) contends that a person will apply more effort in exhibiting a behaviour when his or her perception of behavioural control is high. Therefore, a person's perception of control over a behaviour together with intentions, is expected to have a direct effect on behaviour, especially when perceived control in an accurate assessment of actual control over the behaviour and when volitional control is not high.

The TPB also proposes that perceived control is an independent determinant of behavioural intention as well as attitude toward the behaviour and subject norm. Thus, with attitude and subjective norm held constant, a person's perception of the ease or difficulty of behavioural act will affect his or her behavioural intention. According to the TPB, perceived control of behaviour is determined by *control beliefs* concerning the presence or absence

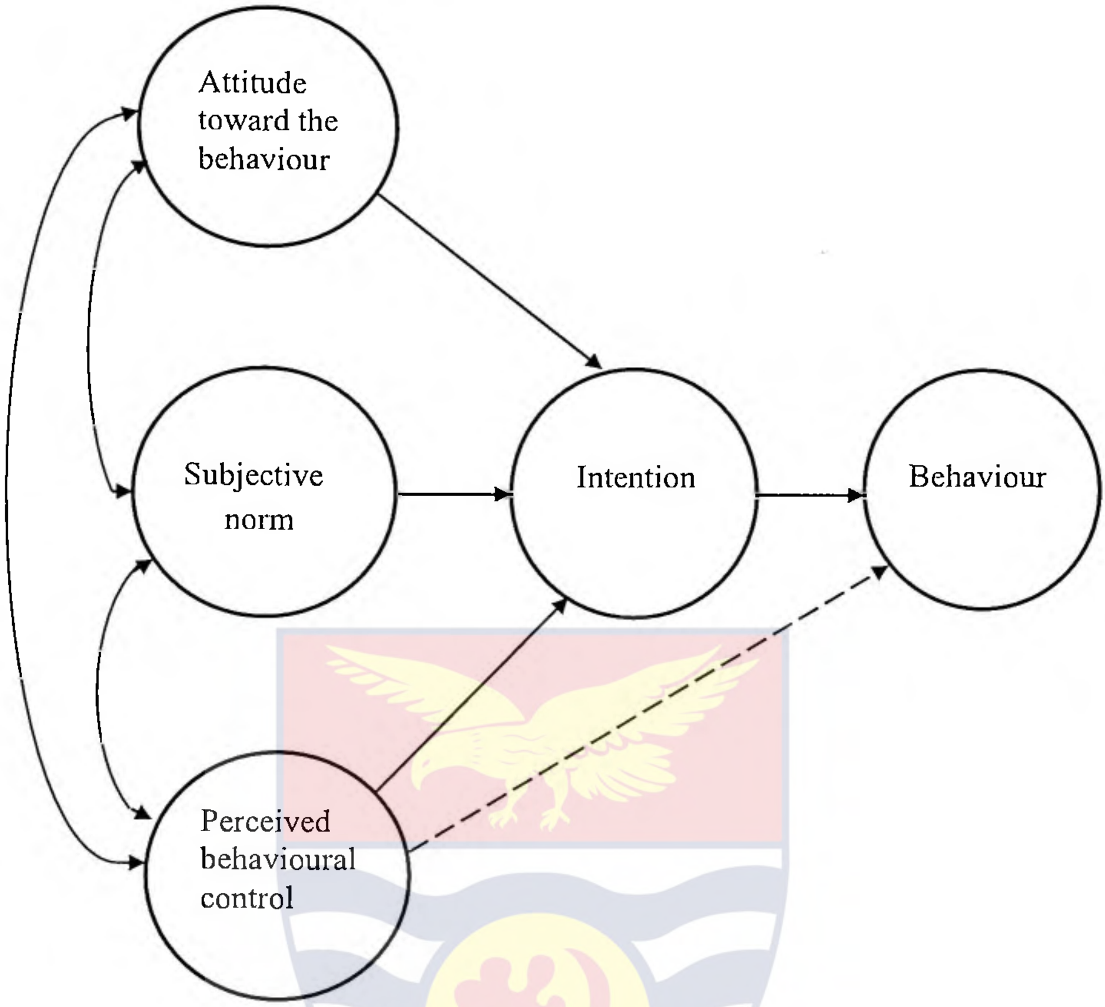


Figure 3: Theory of Planned Behaviour

Source: Ajzen (1991)

of facilitators and barriers to behavioural performance, weighted by the *perceived power* or impact of each factor to facilitate or inhibit the behaviour. Thus, a person who holds strong control beliefs about the existence of factors that facilitate the behaviour will have high-perceived control over the behaviour. On the other hand, a person who holds strong control beliefs about the existence of factors that impede the behaviour will have low perceived control over the behaviour.

It has been observed that TPB better predicts health-related behavioural intention than the theory of reasoned action since it covers people's non-volitional behaviour, which cannot be explained by the theory of reasoned action (Ajzen, 1989). However, the theory is based on cognitive processing and level of behaviour change. As such, some health behaviours and other types of behaviours may be largely influenced by strong emotions (Dutta-Bergman, 2005).

Empirical research has supported the TPA. Research suggests that changing TPA constructs successfully predict and explain behaviour. For example in the study of HIV/STD prevention behaviour, Bosompra (2001), found that an increase in control over behaviour increased the likelihood of condom use among university students in Ghana. Similar results were reported among African American female adults in their use of female condoms when more control was offered to them (Bogart, Cecil, & Pinkerton, 2000).

The Health Belief Model

The Health Belief Model (HBM) was originally developed in the 1950s to predict people's participation in programmes that prevent and detect diseases such as tuberculosis (Rosenstock, 1960; Becker & Rosenstock, 1984; Rosenstock, Strecher, & Becker, 1988). The model was extended to study the responses of peoples to disease symptoms and their behaviours in response to diagnosed illness, especially adherence to medical regimens (Glanz, Rimer, & Viswanath, 2008). The model aims to explain preventive health behaviours rather than behaviours in time of illness (Ben-Natan & Adir, 2009) (Figure 4).

The HBM has three fundamental components: individual perceptions, modifying factors and factors influencing the likelihood of individuals undertaking the recommended preventive health action (Glanz, Rimer, & Lewis, 2002).

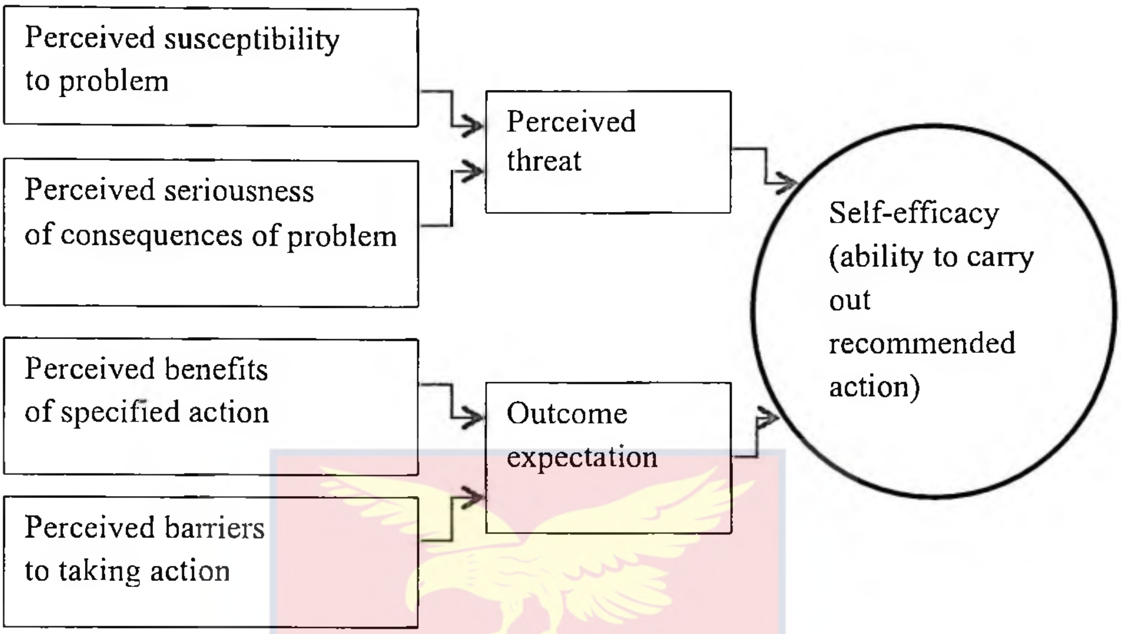


Figure 4: The Health Belief Model

Source: Rosenstock et al. (1988)

The HBM has four constructs: perceived susceptibility, perceived severity, perceived benefits and perceived barriers. These constructs represent people's readiness to act. Later modifications have included cues to action indicating readiness to and stimulation of behaviour. The underlying concept of the model is that health behaviour is determined by personal beliefs or perceptions about a disease and the strategies available to decrease its occurrence (Rosenstock et al., 1988). The Health Belief Model contains several primary concepts that predict why people will take action to prevent, to screen for, or to control disease conditions. The model assumes that health behaviours are motivated by five elements of perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers to behaviour, cues to action and perceived self-efficacy (Champion & Skinner, 2008).

The HBM has undergone reviews due to its inability to predict 'other forces' such as social, economic and environmental conditions that affects behaviour (Nutbeam & Harris, 2004). Nejad, Wertheim and Greenwood (2005) has pointed out that the HBM has no strict guidelines as to how the different variables predict behaviours. Instead, the HBM proposes that individual characteristics (including age, education) are likely to contribute to the prediction of health behaviours. Nejad, Wertheim and Greenwood (2005) add, however, that although this lack of structure for the HBM is often a source of criticism, the flexibility of the model might make it more adaptable to predicting a variety of behaviours.

According to Nejard et al. (2005) and Glanz et al., 2002, the HBM is based on the assumptions that a person would plan to take a health-related action if that person feels that a negative health condition (cervical cancer) could be prevented or cured; has a positive expectation that by taking a recommended action (cervical screening or treatment) she would avoid a negative health condition (advanced cervical cancer stage or death); and believes that she could successfully plan and take a recommended health action (undergo cervical screening and adhere to recommended actions).

The constructs of the model indicate that, perceived susceptibility is a person's belief about the chances of contracting a health condition or one's opinion or one's chances of getting a condition. This also includes acceptance of diagnosis in cases of existing health problems (Glanz et al., 2002). However, individual differences play an important role in the process of symptom detection, and before a decision is made to seek professional advice for suspected illness.

People focus mostly on symptoms that involve pain, discomfort or one's inability to function normally. This poses a problem in cases where the condition does not show signs in the early stages, like cervical cancer. Nevertheless, individuals who believe that they are at increased risk or are vulnerable to certain forms of illnesses are likely to be particularly vigilant or on the lookout for associated signs and symptoms (Russell et al., 2006).

Perceived severity is a person's belief about the seriousness of contracting a health condition or opinion of how serious a condition is and what its consequences are (Glanz et al., 2002). Together, perceived susceptibility and perceived severity comprise what is known as the perceived threat of illness, sometimes known as vulnerability. Perceptions of severity may be subjective. This could be associated with factors such as socialization, beliefs and educational background.

Perceived severity can also be affected by emotional state, which may result in a decrease or increase in the likelihood of health seeking behaviour. For instance, if an individual is anxious, it may lead to denial or sensitivity, thereby misinterpreting normal physiological responses as signs of illness or dysfunction. In extreme cases, an individual may constantly focus on internal, somatic stimuli and be consumed by concerns about some underlying pathology as a result of fear of the disease. Some individuals also perceive severity when they consider the associated consequences of pain, death and financial expenses (Russell, Champion, & Skinner, 2006). In this study, perceived seriousness is defined as knowledge about the fear associated with the condition and the progression of cervical cancer.

Perceived benefits refer to a person's beliefs about the effectiveness of a strategy to reduce the threat of illness or one's belief in the efficacy of the advised action to reduce the risk of seriousness of impact (Glanz et al., 2002). The likelihood of an individual engaging in health seeking behaviour is associated with the perceived barriers. In this case, an individual would be weighing the costs against the gains. Thus, if seeking health actions would address the perceived susceptibility and severity associated with a disease, the cost of the action is seen as minimal compared to the benefit of the action (Russell et al., 2006). In the context of this study, perceived benefit is defined as the benefits associated with early screening and treatment of the condition.

Perceived barriers are a person's beliefs about the potential negative (tangible and psychological) consequences of adopting the health strategy or one's opinion of the tangible and psychological costs of the advised actions (Glanz et al., 2002). These are aspects that affect one's willingness to perform a positive health action. They would contradict an individual's intended action despite being given the correct information. Perceived barriers could be symptoms of disease, conditions carrying a social stigma, cultural influence of witchcraft, association of conditions with old age, procedures perceived as painful, fear of test results or time-consuming issues (Leyva, Byrd, & Tarwater, 2006; Russell et al., 2006).

'Cues to action' refers to events or experiences that could be personal (such as physical symptoms of a health condition), interpersonal, environmental, media-related publicity that could motivate a person to take action or adopt a strategy to activate readiness (Glanz et al., 2002).

Perceived vulnerability and severity of a condition could lead to the likelihood of taking action. Cues to the perceive vulnerability and susceptibly can be received from the illness experience of relatives' and/or friends' illnesses, health promotion campaigns, lay-referral systems, articles in newspapers or magazines, pressure to take action coming from third parties such as spouses, friends or employers (Russell et al., 2006). For the purpose of this study, cues to action had been defined as the personal experiences of patients with the symptoms and signs of the disease that prompted the screening and treatment of the patient.

Self-efficacy refers to the ability of a person to adhere to preventive health action depending on one's self-confidence in executing, promoting and preventing health activities (Glanz et al., 2002). In this study, self-efficacy has been used to represent the ability of patients to develop coping mechanisms to the condition. Modifying factors are defined as demographic, socio-psychological and structural factors, which serve to condition an individual's perceptions (Glanz et al., 2002).

The Concept of Biographical Disruption

The concept of biographical disruption was introduced by Bury (1982) when he studied a series of rheumatoid arthritis patients over three years in England (Bury, 1982). His conclusion was that chronic illness brings about disruption to a patient's life trajectory and biography. In other words, the disease creates discontinuity in the life of patients. He argued that the lives of people living with chronic illness are disrupted and full of uncertainties.

The situation makes them focus on their bodily sufferings, resulting in ruptures between body, self and society (Bury, 1982; Williams, 2000).

Bury (1982) argues that the onset of a chronic disease brings pain, suffering and death to the fore, things that are normally seen as distant possibilities in ones' life or perceived as the problem of other people. As a result of this, suffering people's life trajectories are disrupted. To manage the disruption experienced due to chronic illnesses disease, Bury (1982) suggests three concepts: coping, strategy and style. 'Coping' refers to the emotional methods adopted by a person to manage situation. 'Strategy' refers to the actions the ill person adopts to deal with the illness, while 'Style' reflects the notion that different people have different attitudes towards illness.

The concept has been used in cancer studies such as lung cancer (Leveälahti, Tishelman, & Ohlén, 2007), colorectal cancer (Rozmovits & Ziebland, 2004) and cervical cancer (Hubbard & Forbat, 2011). These studies have showed that living with cancer alters the identity of the individual and leads to loss of control over body functions (Rozmovits & Ziebland, 2004; Leveälahti et al., 2007). Among cervical cancer patients, the condition is seen as a permanent threat to life (Hubbard & Forbat, 2011). These losses have symbolic meaning for the personal identity, social relations and intimate relationships of the patients.

Socio-Ecological Model

Over the past three decades, the ecological approach has generated much interest and enthusiasm among researchers and interventionists. As a result, a number of ecological models focusing on health behaviours and public health outcomes have emerged (Richard, Gauvin, & Raine, 2011). Popular among these models include that of Bronfenbrenner (1979), McLeroy, Bibeau, Steckler, and Glanz (1988), Sweat and Denison (1995), Stokols (1992) and Blum et al. (2002) among others. In the model of McLeroy et al (1988), two key concepts are formed: multiple levels (behaviour affects and is affected by multiple levels of influence) and reciprocal causation (individual behaviours shape, and are shaped by the social environment).

In the model, patterned behaviour is the outcome of interest and behaviour is viewed as being determined by intrapersonal, interpersonal, institutional, community and public policy factors (Figure 5). An implicit assumption of these levels of analysis is that health promotion interventions are based on our beliefs, understandings and theories of the determinants of behaviour, and that these five levels of analysis reflect the range of strategies currently available for health promotion (McLeroy et al., 1988). The intrapersonal factors include characteristics of the individual such as knowledge, attitude, behaviour, self-concept, skills and demographic characteristics of individuals.

These factors predispose individuals to act and respond to behaviours differently. For example, in a study on smoking cessation, individuals with higher education were more likely to quit than those with no education (Sallis, Owen, & Fisher, 2008). The interpersonal factors examine issues within the social environment that influences a person's behaviour (National Cancer Institute, 2005). These are interpersonal processes and primary groups (formal and informal social network and social support systems) such as the family, work group and friendship networks (McLeroy et al., 1988).

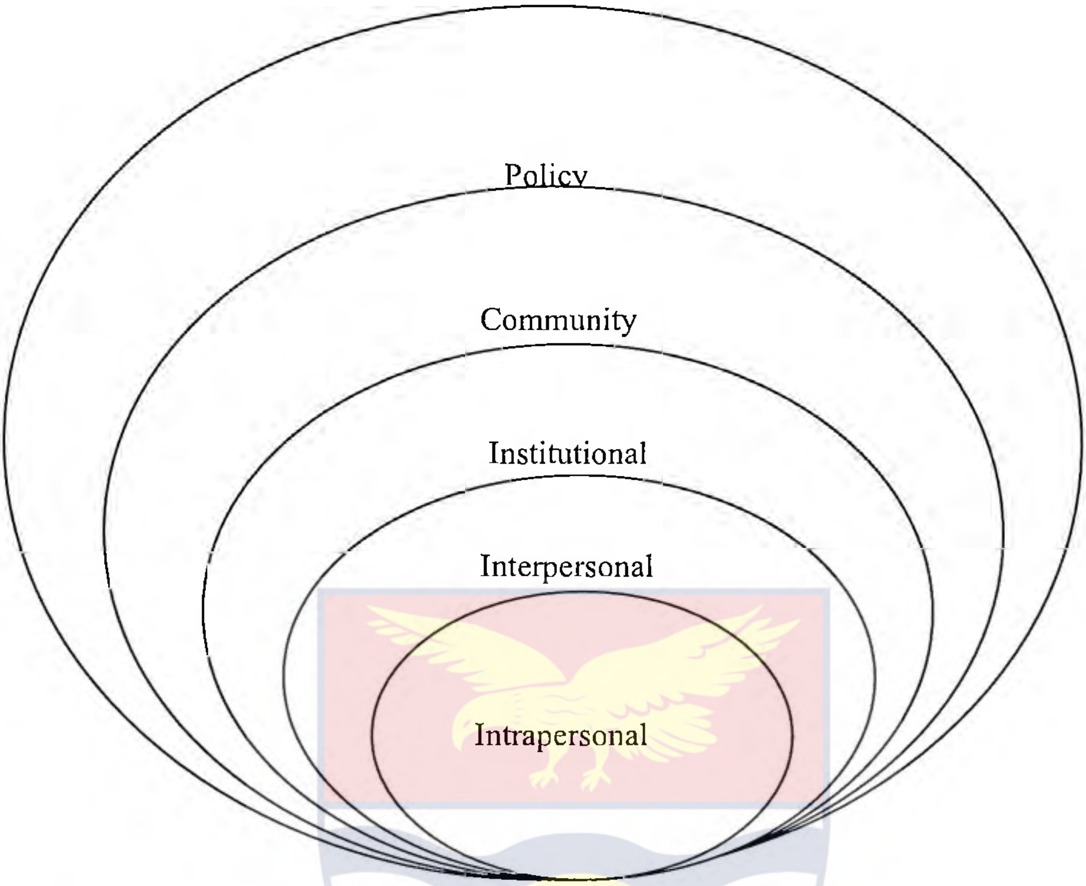


Figure 5: Socio-Ecological Model for Health Promotion

Source: McLeroy et al. (1988)

The interpersonal level measures the effect of an individual's social environment on health behaviours and the reciprocal effect of the individual on these factors. The institutional factors include social institutions with organisational characteristics and formal (and informal) rules and regulations for operation that constrain or promote behaviours. The community factors also include relationships among organisations, institutions and informal networks among defined boundaries (McLeroy et al., 1988). The public policy factors therefore include local, state and national laws and policies that affect behaviours. The model assumes that appropriate changes in the social environment will produce changes in individuals and that the support of individuals in the population is essential for implementing environmental changes (McLeroy et al., 1988). Even though it may be challenging to evaluate all components empirically, the model addresses the importance of directing interventions at changing interpersonal, organisational, community and public policy factors which support and maintain healthy behaviours (McLeroy et al., 1988).

Conceptual Framework for the Study

Although all the four theories seek to explain decisions an individual will take concerning his or her health, this study was guided by the HBM, the Biographical Disruption Concept and the SEM (Figure 6).

At the individual level, this study uses the HBM as a concept to explain the knowledge and perception of cervical cancer patients, analyse various strategies developed by cervical cancer patients to manage the disease, and the knowledge and role of male partners in cervical cancer screening and treatment. In this sense, perceived susceptibility, perceived severity, perceived benefits, cues to action, self-efficacy and modifying factors were the HBM constructs used in the study. The perceived benefits were defined as the benefits associated with early screening and treatment of the condition. Cues to action were defined as the patient's experience of symptoms and signs of cervical cancer that prompted patient to seek treatment.

The concept of biographical disruption has been used as a conceptual framework in studying the lived experiences of persons living with chronic illnesses such as AIDS (Buki, Kogan, Keen, & Uman, 2005); stroke (Faircloth, Boylstein, Rittman et al., 2004) and diabetes (Rajaram, 1997; de-

Graft Aikins, 2003).

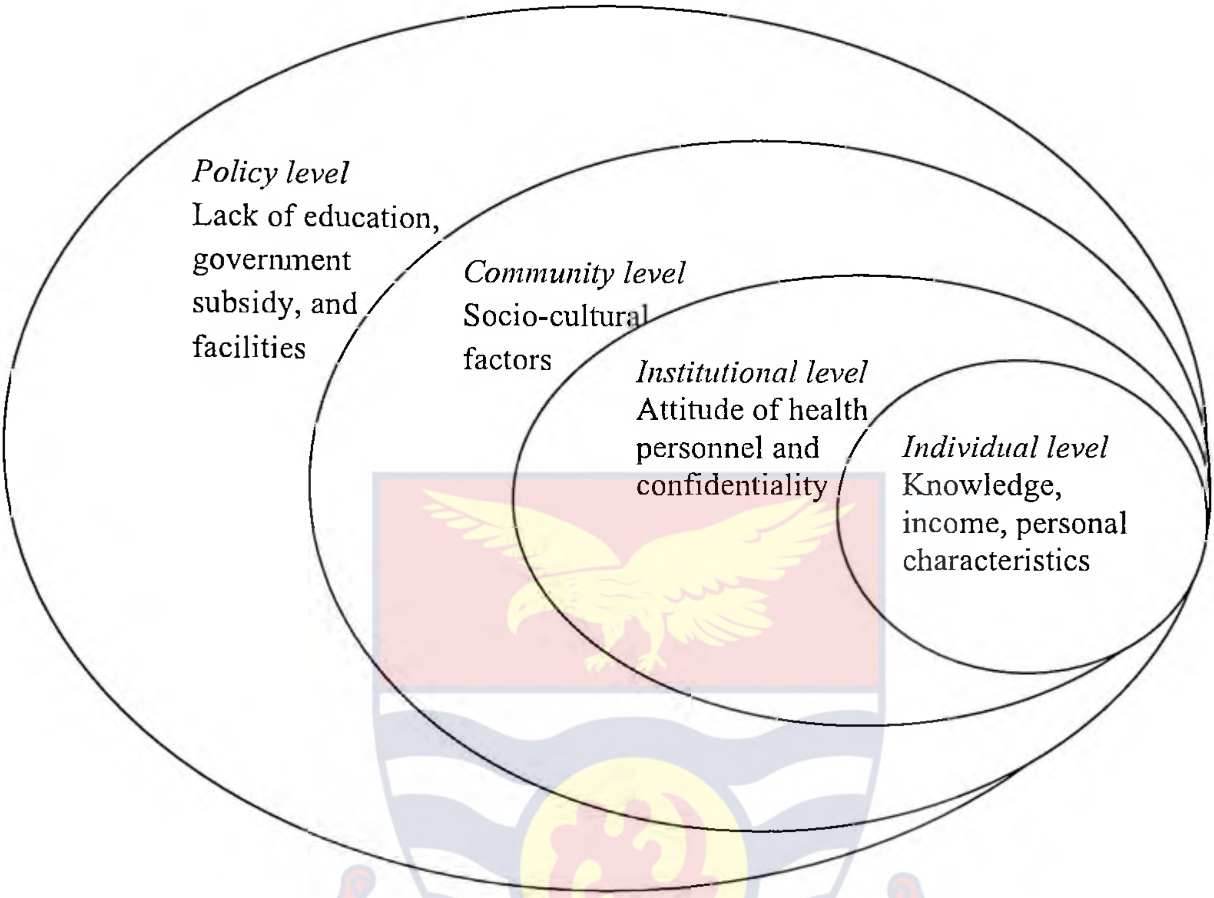


Figure 6: Conceptual Framework for Barriers to Screening and Treatment

Source: Adapted from McLeroy et al. (1988).

Through these studies, chronic illnesses have been found to disrupt the body self, social identity, family and social relationships, career decision and economic condition of participants (de-Graft Aikins, 2003; Faircolth et al., 2004). Drawing on this, this study adopts the concept of biographical disruption to explore the lived experiences of cervical cancer patients and their response to the condition.

The socio-ecological model of McLeroy et al. (1988) was also used to explain barriers to cervical cancer screening and treatment. McLeroy et al.'s (1988) model was chosen among a number of ecological models posited by different proponents because its concepts best suit the emerging themes in the study. The SEM was adopted for the study due to its comprehensiveness and flexibility in capturing factors beyond the individual level. Thus, in the context of this study, it deals with factors that influence health-seeking behaviour at multiple levels. It is also flexible because it can be applied to a number of issues, not just chronic diseases such as cervical cancer.

The five levels of McLeroy et al.'s (1988) model were collapsed into four levels. The intrapersonal and interpersonal factors were merged into individual levels because barriers to screening and treatment are associated with the individual's personal characteristics as well as issues associated with immediate persons. Other aspects on interpersonal relationships can be covered under community level barriers.

The institutional level barriers also considered the attitudes of health service providers and the issue of confidentiality. Community level barriers also captured issues concerning the belief system of the communities in the study while policy level barriers focused on issues concerning funding or government subsidies for screening and treatment, awareness creation on the disease as well as accessibility to screening and treatment facilities.

Implications for the Study

Individual behaviour is determined by a combination of social environment – community norms and values, regulations, and policies. The most effective approach leading to healthy behaviours is a combination of efforts at all levels (Bronfenbrenner, 1979; McLeroy et al., 1988). Cervical cancer is a public health issue of global significance, which affects, not only the sufferers, but also their families, their communities and society (Daley, Alio, Anstey et al., 2011). The Socio-ecological model complements the HBM in terms of ‘other forces’ such as social, economic and environmental conditions (Nutbeam & Harris, 2004; Nejad et al., 2005).

SEM assumes that a single level of influence cannot explain a person’s health behaviour (Bronfenbrenner, 1979). A public health problem such as cervical cancer is seen as resulting from a combination of several factors spanning all levels of the situation (Daley et al., 2011). The Socio-ecological model can assist in capturing the perspectives and factors that influence the decision of women not to go for screening or the refusal of cervical cancer patients to seek treatment.

SEM is particularly useful in understanding the barriers to screening to detect cervical cancer as it allows the examination of the interconnected barriers that operate across and within the various levels (Bronfenbrenner, 1979). For example, community level issues cover family, friends and peers as well as community influences on decision to screen or seek treatment for cervical cancer. These levels of influence could impact positively or negatively on a woman’s decision to screen or seek treatment for cervical cancer (Daley et al., 2011).

The Socio-ecological Model is used to guide the understanding of barriers to screening and treatment at multiple levels and other influencing factors that are beyond the control of women in the choices they would make concerning their health. Women who suffer from cervical cancer face a double agony of dealing with a debilitating disease that is associated with stigma and isolation as well as issues of sexuality and sex negotiation. The Concept of Biographical Disruption assisted in capturing the lived experiences of women suffering from cervical cancer.

CHAPTER FOUR

METHODS OF DATA COLLECTION AND ANALYSIS

Introduction

This chapter presents the methods that were used in conducting this study. It describes the study setting, the study population, sources of data for the study, sampling procedures and size, data collection instruments, ethical considerations and methods of data processing and analysis.

Study Setting

The research was carried out at the Battor Catholic hospital, situated in the North Tongu District of the Volta Region of Ghana. The hospital was selected for this research purposely because it is the only health facility in the Volta Region that functions fully as a centre for cervical cancer screening and treatment. The hospital also continues to be the major referral centre in the catchment area and for other areas in Greater Accra, Eastern and Volta Regions (Effah, 2011).

Located on the western shores of the Volta River and about 30 kilometres up-stream from Ada, the hospital is about 100 kilometres from Accra. The hospital is about 18 km off the Accra to Aflao highway at Sege in the Dangme East District of the Greater Accra Region (Figure 7). The hospital provides a 24-hour service and meets health needs of its clients. It has 14 doctors including 6 specialists, 6 medical officers and 1 resident doctor; 5 physician assistants and 60 nurses. Occasionally, the hospital receives medical specialists from Europe to attend to various cases.

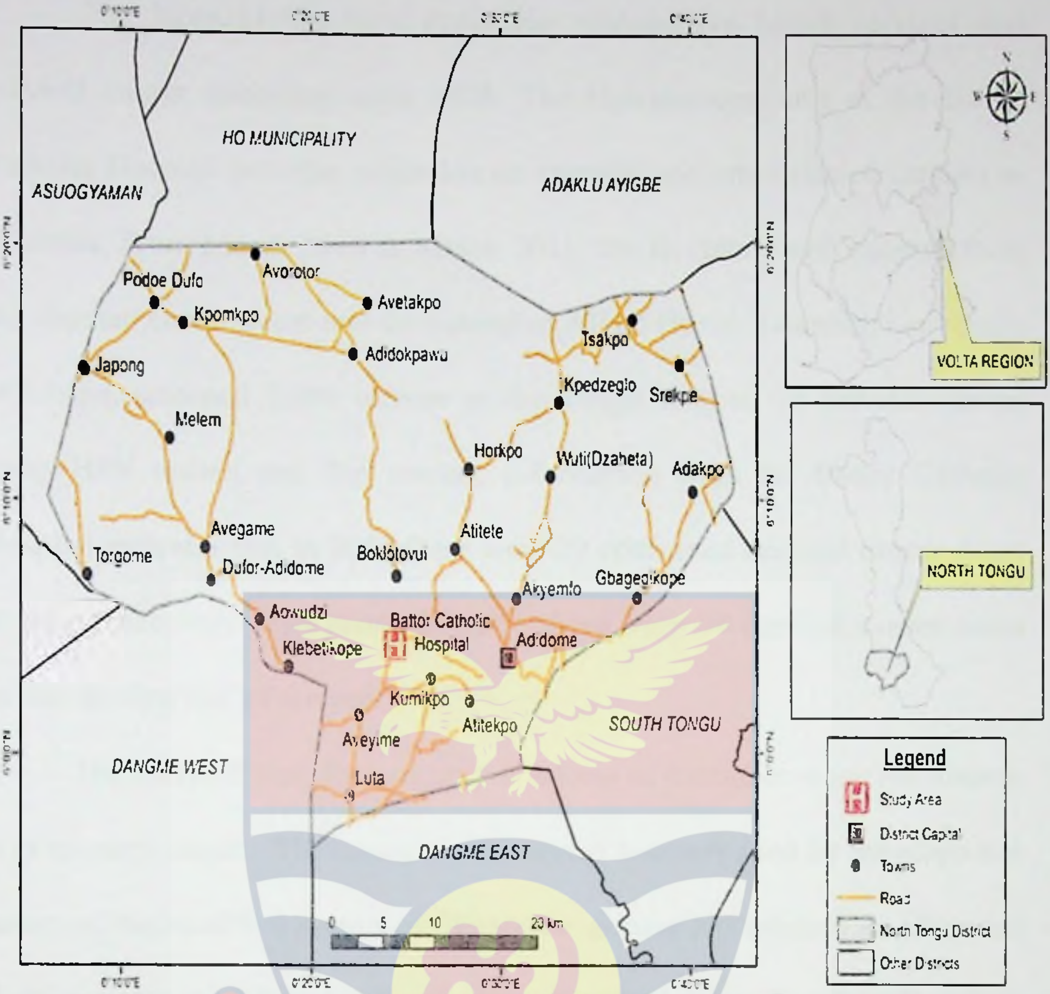


Figure 7: Map of North Tongu district

Source: Department of Geography and Regional Planning, UCC (2015)

For instance, gynaecologists and urologists from Germany have provided services at different points in time. One of such visits occurred in the course of this study. Services provided by the hospital includes obstetrics and gynaecology, reproductive and child health, eye care, HIV/AIDS counselling and testing and ART, internal medicine, surgical services, technical services such as laboratory, X-ray, ultra sound as well as inpatient and outpatient services.

The Hospital has been providing reproductive health services and cervical cancer screening since 1975. The Gynaecology unit of the Battor Catholic Hospital provides education on cervical and other related cancers at its clinic. From March 2010 to March 2011, the Hospital, with support from the German Government and the School of Allied Health Sciences, University of Ghana, screened 3,000 women in the Tongu district for cervical cancer using HPV testing and Pap smears. Information from the Battor Catholic Hospital indicates that in 2013 there were 29 confirmed cervical cancer cases at the gynaecology department. In 2014, there were 14 cervical cancer cases within the first half of the year

The Hospital also does surgery as a form of treatment when the disease is in its early stages. The nature of the surgery is determined by the stage and nature of the condition presented. Where the disease has reached an advanced stage, patients are referred to Korle-Bu or Komfo Anokye Teaching Hospitals for chemo-radiation. The Hospital also uses the 'see-and-treat' methods such as the VIA. The population of the immediate area of the hospital is about 37,000. North Tongu District has a population of 89,777 with 47.3 per cent males and 52.7 per cent females (Ghana Statistical Service, 2012).

Study Paradigm

This study adopted a qualitative methodology. Qualitative methodology is grounded in the interpretivist paradigm of research (Bauer & Gaskell, 2000). The purpose of interpretivist research is to understand and interpret human behaviour rather than to generalise and predict causes and effects. Thus, for an interpretivist researcher, it is important to understand the motives, meanings, reasons and other subjective experiences that inform the actions of individuals (Silverman & Marvasti, 2008). The interpretivist approach helped in understanding the experiences of the cervical cancer patients, the decisions they took concerning the disease, as well as the choices of other respondents about screening and treatment uptake.

Methods of Data Collection

Three different methods were used for the collection of data: in-depth interviews, focus group discussion and observation. The interviews and discussions were tape-recorded and transcribed according to the category of respondents. It has been observed that while individual interviews and focus groups suffer from some common methodological shortcomings since both are interviews of a kind, their distinct characteristics also result in individual strengths (Shenton, 2004).

The individual interviews with cancer patients were to examine the experiences of cervical cancer and their biographies. The individual interviews with health workers were to tap into structural level factors influencing cervical cancer screening and treatment. The focus group discussions were to understand societal perceptions of cervical cancer screening and treatment.

In-depth interviews with the cervical cancer patients were deemed useful for the analysis of knowledge and perception about screening and treatment of the disease as well as coping mechanisms from the perspective of patients. This was done in order to create knowledge about the personal and lived experiences of patients as they went through the screening and treatment processes. In-depth interviews were also done with partners of patients as well as health personnel and these were used to analyse their opinions concerning support provided to patients and barriers to the uptake of screening and treatment.

Focus group discussions with women and men living in the Battor community were conducted to analyse the barriers to the uptake of cervical cancer screening and treatment in the community. This was to create knowledge about why the women would not go for screening and treatment as well as understand what the men think are the factors constraining women in the community in terms of screening and treatment of the disease. Observation was also done at the study facility to assess the processes and procedures involved in screening and treatment of disease as well as the attitude of patients and health personnel during these processes.

Combining in-depth interviews, focus group discussion (FGD) and observation tools for the study greatly enriched the data collected. In-depth interviews allowed the cervical cancer patients and their partners to share sensitive issues and personal experiences concerning a genital disease such as cervical cancer. Focus group discussions (FGDs) facilitated the collection of divergent views and interactions among community members that further enriched the understanding of the perceptions, beliefs and norms of communities around the Battor Catholic Hospital, a health facility that has played a pioneering role in cervical cancer screening and treatment since the 1980s.

Field observations helped in understanding how health facilities and service providers promote or hinder the screening for cervical cancer and treatment of the disease. The use of the various tools helped to enrich the data collected and to confirm earlier studies that sought to identify the barriers to cervical cancer screening and treatment.

Population of Interest and Inclusion Criteria

Five population groups were of interest to this study. These were: (1) women aged between 30 and 65 years attending or who had attended the Gynaecology Unit of the Battor Catholic Hospital and had been diagnosed of cervical cancer; (2) women aged between 30 and 65 years living in the Battor vicinity who had never been screened for cervical cancer; (3) males aged 30 years or older who were living near the Battor Catholic hospital; (4) partners of women with cervical cancer and (5) health professionals working with cervical cancer patients at the Hospital.

Procedure for selection

The Gynaecology Department of the Battor Catholic Hospital was the entry point through which contacts were made with respondents of the study. Cervical cancer patients and their partners, women from the Battor community who had never been screened for cervical cancer and health personnel were purposively selected for this study.

Cervical Cancer Patients

Fifteen cervical cancer patients were selected based on the following criteria: if they were diagnosed with cervical cancer by the Gynaecology Unit at Battor Catholic Hospital and women between 30 and 65 years. The selection of cervical cancer patients for the study started with a review of records of patients from the unit's cancer registry to identify patients who had been diagnosed of cervical cancer. With the help of a nurse, sixty patients were identified from the register. This was followed by phone calls by a nurse to the patients. Even though the target for the cervical cancer patients was 20, fifteen participants who were willing to participate in the study were selected. The number reduced to 15 because it was difficult to trace the patients from the hospital records. Besides, at that particular point, responses from the respondents became similar which indicates the principle of saturation (Guest, Bunce, & Johnson, 2006). However, the reduction of the targeted number to 15 did not affect the results of the study.

The cervical patients were either at the early stage of the diagnosis of the disease, had undergone surgery or undergone treatment. However, cervical cancer patients who were in critical condition were excluded. Also, women who had undergone total hysterectomy (removal of the cervix) were not included in the study. The selection of women in the age range of 30-65 was informed by the guidelines of the WHO (2013) which recommends that at a minimum, every woman between 30 and 49 years of age should have cervical cancer screening, at least once in a life time. WHO recommends that screening should continue till age 65 during the second peak of the disease. Research has also shown that, the prevalence rate of HPV is highest among women in their reproductive age and older, with a second peak among post-menopausal women (WHO, 2013; Erickson et al., 2013).

Partners of Cervical Cancer Patients

The study also included partners of cervical cancer patients. The men were interviewed to examine the effects of the disease on their relationship with their partners and their contribution to the health seeking behaviour of the patients. Six partners of cervical cancer patients in the study were selected based on their willingness to participate. Fifteen partners were targeted but the number reduced to six (6) because some of the patients were widowed or divorced. A number of the men were also not willing to participate for various personal reasons. The reduction of the number of partners, however, did not affect the results. This is because the six partners who participated in study gave similar responses, indicating a point of saturation.

Women who have never been Screened for Cervical Cancer

Women who have never been screened for cervical cancer but were residents of Battor and aged between 30 and 65 years were included. Women who had never been screened for cervical cancer were recruited in two ways: (1) the registered patients with the Gynaecological Unit for other ailments were contacted by phone and invited to participate in the study (2) willing patients visiting the hospital were also invited to participate. In-depth interviews were conducted with 10 women who were registered with the Gynaecology Unit at Battor Catholic Hospital, but had never undergone cervical cancer screening.

Health Workers

Health workers play an important role in cervical cancer screening uptake. A study to assess the knowledge and awareness of cervical cancer prevention among Cameroonian healthcare workers found that creating awareness among health care workers on risk factors and current methods for screening was found to be an essential step toward implementing prevention programmes (McCarey & Pirek, 2011). The study therefore included health workers to assess their knowledge of barriers to cervical cancer screening and treatment. Five health personnel were targeted and selected. These were, an oncologists and four (4) nurses who had worked at the Battor Catholic Hospital Reproductive Health Clinic for a minimum of one year and were willing to participate in the study.

Focus Group Discussion for Residents of Battor

Participants for the focus group discussions were first invited to participate in the study through the use of a public address system in the Kekpo and Lasivenu communities. The assemblymen of the two communities and a community health nurse assisted in the recruitment of participants. Twenty women who were resident in the Kekpo community and 10 female patients of the Battor Catholic Hospital were selected for three focus group discussions. There were 10 women in each group. Two focus group discussions were held in the Kekpo community. One group had younger women aged 35 – 45 years while the other group had older women between the ages of 46 – 65 years. This arrangement was to allow free discussions among the younger women without any intimidation from the older women in the community. The third female group discussion was held at the Battor Catholic Hospital to check whether women who are registered at the Outpatients Departments had any knowledge about cervical cancer screening and treatment by virtue of their association with the health facility.

Sixteen men resident at Battor participated in two focus group discussions. Each group comprised 8 men from the Kekpo and Lasivenu communities. It was important to include men in the study because they play a significant role in the health behaviours women and should therefore be involved in programmes on the health of women (Williams & Amoateng, 2012).

The decision to hold three female group discussions as against two for the males, was based on the fact that even though men may be affected indirectly by the disease, cervical cancer is a women's disease. Women should therefore have more say on the issues pertaining to it. Hence, the study considered it appropriate to have more women participating in the discussions. The principal investigator also felt that five (5) focus group discussions were enough to capture the community perspectives.

Study population

Thirty-six respondents participated in in-depth interviews. These were 15 cervical cancer patients and 6 partners of cervical cancer patients, 10 community women who had never screened for cervical cancer and five key health personnel who dealt directly with cervical cancer patients (Table 2). One of the health personnel was a senior obstetrics and gynaecological specialist, two general nurses, one public health nurse and one enrolled nurse.

Table 2: Summary of Characteristics of Respondents for In-depth Interviews

Category of respondent	Age (years)	Number
Cervical cancer patients	34-63	15
Partners of cervical cancer patients	40-63	6
Women who had never been screened	31-46	10
Health Personnel	24-47	5
Total		36

Source: Fieldwork 2014

Figure 3 represents a summary of characteristics of respondents for the five (5) Focus Group Discussions (FGDs) held. A total of 46 respondents participated in the FGDs, comprising 16 men and 30 women.

Table 3: Summary of Characteristics of Respondents for Focus Group Discussions

Type of FGD	Age composition (years)	No. of participants	Location
Male	35-65	8	Kekpo
Male	35-65	8	Lasivenu
Female	35-45	10	Battor Catholic Hospital
Female	35-45	10	Kekpo
Female	46-65	10	Kekpo
Total		46	

Source: Fieldwork (2014)

The focus group discussions were meant to explore the norms, beliefs and cultural practices that could prevent or promote cervical cancer screening among women in the community. The discussions were organised separately for males and females from the surrounding villages of Kekpo and Lasivenu. These villages were selected because of their closeness to the Battor Catholic Hospital.

Data Collection Instruments

Data collection consisted of in-depth interviews, focus group discussions and observation procedures at the Gynaecological Unit of the Hospital. Consequently, in-depth interview guides, focus group discussion guides and an observation guide were developed. In-depth interview guides were developed for cervical cancer patients, partners of patients, health personnel and women who had never been screened (Appendices 5 - 11).

In-depth Interview Guide for Cervical Cancer Patients

The in-depth interview guide comprised issues on how the disease began, screening services, diagnosis and treatment as well as personal experiences with the condition (Appendix 5). Six key areas covered in the guide were fear of the problem, seeking cancer screening, receipt of cancer diagnosis, barriers, making treatment decisions and subsequent receipt of treatment and follow up care. The focus was to understand issues surrounding screening, diagnosis, treatment and barriers faced or perceived as patients advanced through these processes.

In-depth Interview Guide for Partners of Cervical Cancer Patients

The guide for the partners of patients covered forms of medical help sought for the patient, reactions to the condition, forms of support given and personal reaction to the disease (Appendix 6). The interview guide focused on how partners understood the disease, treatment and management of the disease. The purpose was to assess the knowledge of partners about cervical cancer and their role in the treatment of their wives or partners.

In-depth Interview Guide for Community Women who had never been screened

The in-depth interview guide for women who had never been screened covered their knowledge of cervical cancer, available screening facilities, reasons for not screening and sexual life (Appendix 7). It examined knowledge and perception about the disease and why they had not gone for screening despite the availability of screening facilities at their community.

In-depth Interview Guide for Health Personnel

For the health personnel, the guide comprised forms of tests women went through at screening, duration, cost of screening and treatment, suggestions for promotion of uptake of screening and treatment (Appendix 8). The main purpose of this guide was to assess the knowledge of health personnel about the responses of patients to screening.

Observational Guide

Observation was conducted at the Battor Catholic Hospital. The observational guide focused on processes that cervical cancer patients go through before screening, the screening process and the behaviour of patients during screening (Appendix 9). In addition, the attitude and behaviour of health personnel were also observed. The goal of this exercise was to present a visual framework of the environment in which the study was carried out and make connections of factors that are relevant to the study.

Focus Group Discussion Guide

The focus group discussion guides for men and women were the same (Appendices 10-11). The guide comprised issues on illnesses that affect women in the communities, knowledge of cervical cancer, treatment options available for cervical cancer, factors that prevent women from undergoing cervical cancer screening and treatment, cost of screening and treatment, advice for people about the disease and policy recommendations for government concerning cervical cancer screening and treatment.

Training of Research Assistants and Pre-testing

Three research assistants, all females, were recruited for the study. A three-day training was provided for the research assistants. The first day covered the background to the study, the research problem being studied and the purpose of the study as well as the significance of the study. On the second day, the research assistants were taken through the research instruments to ensure that they grasp the purpose of the study as well as what exactly the research instruments sought to measure. For the third day, the research assistants were trained on how to conduct in-depth interviews effectively, how to adhere to ethical issues and how to ensure the collection of quality data.

The interview guides were pre-tested at the Gynaecology Unit of the Korle-Bu Teaching Hospital in Accra between February 27 and March 1, 2014. The choice of the Korle-Bu Teaching hospital for the pre-testing is that it is a facility, which provides cervical cancer screening and treatment. The Hospital also has a Gynaecological Department that serves as a point of referral for cervical cancer patients. Through the pre-testing, the instruments were refined. For instance, during the pre-testing, issues about screening, diagnosis and treatment were emphasised and probing questions were included. Field activities began on the March 12, 2014 and ended on June 12, 2014.

Ethical Considerations

Approval for the study was sought from the Battor Catholic Hospital and ethical clearance was obtained from the Ethical Clearance Committee (ERC) of the Ghana Health Service (GHS) (Appendix 12). Written informed consent was sought from the participants of the study. To ensure anonymity during the interview three actions were taken. Firstly, the interviews were conducted under trees and secluded rooms. This was to avoid interferences and prevent any eavesdropping by any third party. Secondly, respondents were required not to mention their names during the interview process. Thirdly, the respondents were assured that all information given was used solely for academic purposes and that the information will be kept with utmost confidentiality.

To ensure the psychological health needs of the respondents were met during interview, the following measures were adopted. Respondents were encouraged not to answer any question that they felt would impinge on their privacy in order to safeguard the privacy of information of the respondents. Measures were also adopted to ensure the effective management of any potential negative effect on the respondents. A standby psychologist was provided to help with the psyche of any respondent who might be upset during the interview. Handkerchiefs were given to patients who broke down in the course of the interview and needed to wipe their tears. Health personnel provided counselling to those patients who needed it.

Experiences from the Fieldwork

There were a number of issues that emerged from the fieldwork. These were issues concerning access to hospital records, male participation, sexuality and sensitivity, suspicion and the roles played by opinion leaders and community nurses.

Access to Hospital Records

The Hospital readily made records of participants available. This made it possible for data to be collected. With the Gynaecology Unit of the Battor Catholic Hospital as entry point, it was easy to contact patients and health professionals who directly dealt with cervical cancer patients. However, getting the cervical cancer patients to participate in the study proved challenging. Nevertheless, considerable efforts were made to convince patients to participate in the study. It appeared that patients wanted to avoid re-enacting the traumatic painful experiences they had gone through or continue to endure as a result of the disease.

Secondly, telephone numbers provided by some of the patients were not correct. The inaccuracy of the contact information of patients made it difficult to trace some patients. Consequently, patients with incorrect contact numbers were excluded from the study. Patients who had died due to the disease were automatically excluded from the study.

Male Participation

It was difficult to get male partners to participate in the study because of their busy schedules at their various work places. The researcher had to make several calls to negotiate with the partners of the patients to convince them to find a convenient time and place to participate in the study. It took at least a week to convince some of them to participate in the study. Some of the men, especially those in polygamous relationships, were unwilling to be associated with their partners who were suffering from cervical cancer or talk about the disease. It was difficult for them to explain their attitude. In the end, only six male partners, out of the 10 that were supposed to be interviewed, eventually consented and convenient times were arranged for them to participate in the study.

Without the support of a community health nurse and the assemblymen of the areas, it would have been impossible to get the men to participate in the focus group discussions. Only eight showed up for first FGD for the men. A new date had to be fixed for a second focus group discussion in another location for men. However, once the discussions got underway, the men became interested. For most of them, it was their first time of hearing about cervical cancer. A forum was immediately organised after the FGD to educate them on the disease, after which they expressed their willingness to encourage their wives and female family members to go for screening.

Issues of Sexuality and Sensitivity

Cervical cancer patients were initially hesitant about discussing their condition as they felt it was too sensitive and 'too private' an issue to discuss with others. This could be because cervical cancer is a genital cancer and many women felt it was wrong to openly discuss issues about their sexual organs and private sexual lives.

Reaction of Relatives of Patients to the Study

Relatives of some cervical cancer patients were suspicious and apprehensive about the real intentions of the study. The relatives felt the patients could be stigmatised because of the association of the disease with sexual activity and the bodily location of the disease. Some relatives felt the interviews would evoke bad memories of the painful experiences the patients went through. It took a lot of persuasion to convince some relatives that the study was for academic purposes and had no hidden agenda before they allowed the patients to participate.

Role of Opinion Leaders and Community Health Nurses

A community health nurse assisted in mobilising respondents, and with the assistance of the assemblymen of the areas ensured their participation. Even though discussions were to start at 9 am, by 6 am, over 30 women had assembled and it took a lot of efforts to decide who should take part in the discussion as more women showed up than required. After the FGDs, the community health nurses used the opportunity to educate the women about the disease and to encourage those women who had not gone for screening to do so.

Data Validity and Reliability

Over the past decades, a lot has been achieved by proponents of qualitative research in demonstrating the rigour and trustworthiness of their favoured form of research. These involve a range of strategies that may be adopted by a researcher to ensure that their work is academically sound. They include credibility (demonstration that a true picture of the phenomenon under study was presented), transferability (whether the findings can be applied to other settings), dependability (ability of future investigators to repeat the study) and conformability (demonstration that findings emerged from the data and not their own predispositions) (Shenton, 2004; Porter, 2007; Carcary, 2009; Noble & Smith, 2015).

In order to ensure quality control in qualitative data, some of the recommended activities that were performed included iterative questioning, thick descriptions of the phenomenon, peer scrutiny of the findings, and "reflective commentary" by the principal investigator (Shenton, 2004; Porter, 2007; Carcary, 2009; Noble & Smith, 2015). In this study, member checks, iterative questioning, thick descriptions and peer scrutiny were adopted to check data quality.

One of the most important provisions that can be made to bolster the credibility of a qualitative study is the number of checks done (Shenton, 2004; Lietz, & Zayas, 2010; Harper, 2012). To ensure the accuracy of data collected in the course of the study, checks were conducted immediately after the interviews to verify its trustworthiness. After transcribing and typing the scripts, the tapes were played over to cross check the facts, which were also reviewed by the research team. Interviews, which were conducted in Ewe or Twi, were translated directly into English while transcribing and verified by the team. For iterative questioning, probes were used to elicit detailed data and to uncover any contradictions or falsehoods that emerged. Different methods such as observation, focus groups and individual interviews were also used in order to examine the research questions from different perspectives. Besides, opportunities for scrutiny of the data by colleagues or peers were provided in order to improve the quality of the data.

Data Processing and Analysis

All transcripts went through quality checks by the candidate and then through group discussion with the field assistants. The transcribed interviews were entered into the R-Studio software package for Qualitative Data Analysis (RQDA) for coding and analysis. This programme is useful for organising qualitative data through systematic indexing, annotation, and retrieval functions (Spector, 2004; Kuhnert, & Venables, 2005; Matloff, 2009).

A thematic analysis approach was employed (Thomas & Harden, 2008). The analysis was guided by a coding frame with two sections: 1) a section of pre-existing deductive codes derived from previous cervical cancer research in Ghana (Williams & Amoateng 2012; Williams, 2014; Adanu et al., 2010) and 2) an open-ended section of inductive codes that emerged from the interviews.

The analysis of the life experiences of the cancer patients was guided by the concept of biographical disruption. The analysis was focused on identifying deductive codes such as identity loss, loss of bodily functions, perceptions of threat to life, and economic disruptions (Rozmovits & Ziebland, 2004; Leveälahti, Tishelman, & Ohlén, 2007; Hubbard & Forbat, 2011). In addition, the process of managing the disease was also examined. Inductive codes that emerged from the context were also noted.

In developing the coding frame, the reported barriers were identified as deductive codes and the coding process began with active identification of these deductive codes in the transcripts. The deductive coding stage was followed by the identification of inductive codes. The analysis team was interested in new causal theories outside the existing literature (e.g physical inactivity) as well new sub-themes emerging within existing causal theories (e.g a new aspect of the dietary cause of diabetes). The coding frame was developed through multiple group discussions and informed by structured attention to areas of consensus, conflict and absence in respondents' narratives.

Each study population sub-group was analysed separately. Therefore, separate codes were generated for each of the sub-groups based on their acronyms such as CCP for Cervical Cancer Patients, PCCP for Partners of Cervical Cancer Patients, HP for Health Personnel, WWHNS for Women Who Had Never Screened, WFGD for Women's Focus Group Discussion and MFGD for Male Focus Group Discussion. Participants who participated in in-depth interviews were therefore assigned numbers based on the order in which they were interviewed. As a result, for instance, CCP 1 to CCP 15 were generated to represent the individual patients.

Summary

The study was conducted at the Battor Catholic Hospital in the North Tongu district of the Volta Region by virtue of it being the only health facility that provides screening services to the rural populace in the district and its environs. The study was based on the interpretivist research paradigm, which avoids rigid structural frameworks (as in positivist methodologies) and adopt more personal as well as flexible research structures (Carson, Gilmore, Perry, & Gronhaug, 2001), captures meanings in human interaction (Black, 2006) and makes sense of what is perceived as reality (Carson et al., 2001).

Qualitative data collected involved cervical cancer patients at the health facility, their partners, health personnel, women who had never screened and men living in the study community. Different sets of research instruments were developed for each of these categories of respondents. This was to generate a comprehensive knowledge on the study subject.

CHAPTER FIVE

KNOWLEDGE, PERCEPTION AND EXPERIENCES OF WOMEN LIVING WITH CERVICAL CANCER

Introduction

This chapter presents the findings and discussion of study objective one, on the knowledge, perception and experiences of 15 cervical patients about the disease. This chapter drew on the HBM was applied in explaining the knowledge of cervical patients of the disease before and after diagnosis. The Biographical Disruption Concept of Bury (1982) is used to explore the extent to which women experience cervical cancer as an acute, chronic and life-threatening condition.

The knowledge of patients in relation to the existence of the disease, causes, risk factors, signs and symptoms, screening and treatment options and perceived susceptibility, severity of the disease, personal experiences and prevention was explored and presented in this chapter. In addition, the challenges or disruptions patients faced as a result of the disease are discussed.

Background Characteristics of Cervical Cancer Patients

This sub-section presents a summary of the background characteristics of the 15 cervical cancer patients interviewed. Out of the 15 cervical cancer patients, 6 were aged 50 to 59, 4 were aged 40 to 49 while another 4 were aged 60 to 63. One of the participants had no formal education, 4 had primary school education, 8 of the patients had secondary school education and two had tertiary education. Ten out of the 15 patients were married while the remaining five were divorced, separated or widowed. Also, ten were self-employed while the rest were unemployed. Nine of the patients had from 4 to 6 children while three had 7 or more children. All the 15 cervical cancer patients interviewed were Christians. Eight were affiliated to the Evangelical Presbyterian Church while 5 were affiliated to the Catholic Church. Among the patients, only one smoked tobacco and only four took alcohol.

Knowledge of the Existence of Cervical Cancer

Respondents were asked about what they knew about cervical cancer prior to diagnosis. Their responses were categorised in five themes: knowledge about existence, causes, population at risk, screening options and treatment. This has been presented thematically in Table 4.

Knowledge about existence

All the women interviewed did not know about cervical cancer prior to diagnosis and said they were surprised when they were told about the condition. Some of the comments indicating this were:

> *"I did not know anything about it. I did not even know anything about cancer. I knew it was only breast cancer that can affect women. I did not know there was anything like cervical cancer."* (CCP 2, 52 years).
>
> *"When I began having symptoms, I did not know it was that condition I was suffering from. I did not understand what was happening to me because I had no knowledge of the disease."* (CCP 13, 47 years).

Table 4: Knowledge of Cervical Cancer

Issue	Explanation
Knowledge about existence	All the patients did not know about the disease before diagnosis
Population at risk	13 of the patients did not know the population at risk
Causes	14 of the patients did not know the causes of the disease, only one mentioned HPV and indiscriminate sex.
Screening	None of the patients knew about screening options
Treatment	None of the patients knew about treatment options

Source: Fieldwork, 2014

Thirteen of the respondents had some knowledge of other cancers such as breast cancer, skin cancer, uterine cancer, stomach cancer, mouth cancer and lung cancer, but not about their condition. Cervical cancer patients could also not tell that the initial symptoms had anything to do with the disease. For this reason, they could not understand what was happening to them until they were diagnosed. Two of the respondents expressed the frustration they experienced as follows:

> *"When I was bleeding, I did not know the kind of disease that was causing that to happen. I did not know what was wrong with me and what has caused this because I had stopped my*

> *period for about four years so when it started coming, I was disturbed. I did not understand the reason why it had come to that until I got to the hospital and was told it was cancer".* (CCP 5, 50 years).
>
> *"I did not understand why as a woman who had ceased childbearing, I am beginning to bleed again with vaginal discharge. I did not understand so I was always visiting the hospital with it".* (CCP 11, 55 years).

Three of the cervical cancer patients perceived the initial symptoms of the disease to be symptoms of fibroid.

> *"Whenever I washed my vagina, I felt that something was at the mouth of my womb. But I perceived it as 'kooko' being formed at the mouth of my womb.* (CCP 3, 43 years.
>
> *"It was when I got to Battor that I thought it was fibroid because of the big clots that were coming so I thought it was fibroid. But when they took care of me they saw it was not fibroid because they had time to send my lab to Korle Bu".* (CCP 2, 52 years).
>
> *"I was told by a friend who used to experience the same situation which she called fibroid. Thereafter I thought it was fibroid. I do not know of the local name for this disease".* (CCP 8, 62 years).

Four of the respondents who were 50 years and above, t mistook the initial symptoms of the disease as an indication of menstruation, aging and menopause.

> *"Ooh! I thought maybe because I am growing up so it is like the menses wanted to cease so that was all".* (CCP 2, 52 years).

> *"I thought I was experiencing my menopausal stage, therefore I thought that taking the herbal drugs will cure it.* (CCP 7, 59 years).

> *"I thought it was my period. I was wondering why at this time, after so many years of stopping my menses. It was coming intermittently, that is, it will come for some time, stop and occur again".* (CCP 10, 63 years).

> *"Initially, I thought it was because I was stopping my menstrual period that was why I was bleeding".* (CCP 14, 60 years).

Three of the respondents also thought that the initial symptoms of the disease were a normal condition and not anything serious. As a result, they delayed in reporting to the hospital or health facility until the situation got worse. One of them indicated that:

> *"When I saw it the first time, I thought it was a normal condition because women sometimes get vaginal infection and such symptoms. But when the symptoms persisted before I realised that something was going on".* (CCP 4, 44 years).

Another noted that:

> *"In fact, initially when I was experiencing the symptoms, my sister told me to take it to the hospital. I did not know what kind of sickness it was. So I thought it was not any serious*

> *disease since only my waist was aching. It was when the condition worsened that my sister took me to hospital".* (CCP 5, 50 years).

The lack of knowledge about the disease was a major concern to the respondents as most of them said they would have either gone for screening earlier to prevent the disease or sought help at the early stage of the condition.

Population at Risk

Thirteen of the women did not know about the population at risk for cervical cancer. According to two of the respondents, the population at risk of cervical cancer were in three sub-groups (1) women who have ever given birth (2) all women and (3) everyone (CCP 7 and CCP 10). According to CCP 10, the disease can affect everyone because it is related to reproductive health and once an individual is sexually active they are at risk of the disease. Therefore, cervical cancer can affect women while prostate cancer can affect men.

> *"I think it is all women who are likely to have the disease."* (CCP, 7)
>
> *"Everybody can get affected. The men's own is prostate cancer".* (CCP 10).

Causes of Cervical Cancer

Respondents were asked what they perceived as the causes of the cervical cancer. The participants mentioned four causes of cervical cancer: vaginal hygienic practices, indiscriminate sex, childbearing and HPV virus.

However, 13 of them reported that they did not know the causes of the disease. Two of the women mentioned that the disease could be caused by indiscriminate sex. One respondent explained that indiscriminate sex increases the risk of contracting the HPV virus, which is the main cause of cervical cancer:

> "*From the onset, I did not know the cause of the disease. But after I was diagnosed, whenever there is any cervical cancer program I listen, so I got to know that the disease is caused by indiscriminate sex and it is a virus. That is what I know about it."* (CCC 6, 63 years).

A respondent in her menopause perceived cervical cancer as the consequence of child bearing among women:

> *"Well, until I began coming here, I thought that it is as a result of childbearing. When you are done with child bearing, this could be the side effects of it".* (CCP 14, 60 years).

In spite of the knowledge of the respondents about the causes of the diseases, there was a difference in what they perceived as causes of cervical cancer and the cause of their condition. The respondents reported that they never thought they were vulnerable to such a disease because they thought that they had not done anything that may put them at risk of the disease. To illustrate, the comments of two women are presented below.

Case studies

CCP 6 is a 63-year-old woman with three children. She is separated from her husband due to cervical cancer. She is a Christian and a retired educationist. When asked what causes cervical cancer, her first response was

"*I do not know.*" Later during the interview she mentioned that from the news, she got to know that the disease could be caused by "*indiscriminate sex and it is a virus.*" Yet when she reflects over her life, she gets confused because she was not involved in indiscriminate sex and her neighbours could attest to that:

> "*But if I look at myself and my lifestyle I do not know what really went wrong because I won't praise myself but people can testify that I am not in the category of people who had sex indiscriminately*".

CCP 7 is a woman aged 59 years and with four children. She is separated from her husband. According to her, she had learnt that cervical cancer can be caused by improper vaginal hygienic practices such as douching with local herbs, and inserting the hand in the vagina. However, she reported that she did not know what caused the disease:

> *"I do not know. I can't think of anything because I always think about it. This question is always on my mind. Then I ask myself, I do not douche. I do not insert medicines. I don't know. So these questions baffle me. I ask myself I don't put my hands into my womb. My friend the nurse, told me to wash my vagina without putting my fingers there and I have adhered to that. So I don't know. In fact, I have no knowledge of the cause of the disease."*

Evidently, from the accounts of the women, the real cause of cervical cancer is unknown. This is because the known causes conflicts with their lifestyle. This conflict makes them question the causes of the disease and why they should be the ones suffering from it.

surgery and radiotherapy. According to the patients, they only got to know about these treatment options during the treatment process when the doctors informed them. This is reflected in the following statements:

> *"The doctor suggested surgery as the other form of treatment for me and also radiotherapy"*. (CCP 7, 59 years).
>
> *"I was told that it will be very difficult for them to operate, so I should take it to Korle-Bu. I went and they made me have series of laboratory tests and scan three different times and thereafter I was made to sleep under a machine. I was then given injection and thereafter, I was operated upon and became okay*. (CCP 8, 62 years).
>
> *"I was asked whether they should take out the disease. And I told them to take everything, even my womb because I did not want to be infected again. They even liked my suggestion. So they took my womb out and later told me about it"*. (CCP 9, 49 years).

These imply that the patients had no knowledge of the screening and treatment options for the disease prior to diagnosis. Their concerns were more on how they could get treated and healed rather than the available treatment options.

Source of Knowledge of the Disease

Health workers and the media were the two main sources of knowledge about cervical cancer. All the respondents said they got to know about cervical cancer only after they were diagnosed. All of the respondents mentioned doctors and nurses as their sources of information of the disease while 2 said they had additional information from television and radio. From the health workers, the respondents said they had information during counselling and treatment processes. From the media, the respondents said they received information on the causes and prevention of the disease:

> *"I got my information from the radio. They were talking about what causes cervical cancer. Sometimes when I come to the clinic the nurses educated us on treatment and encourage us."* (CCP3, 43 years).

Illness Notification

The cervical cancer patients used the changes they experienced to detect that something was not right with them. Ten of the respondents said they experienced persistent bleeding, while 4 of them said they were experiencing a smelly discharge from the vagina. All the 15 cervical cancer patients said they were having bodily pains as well. Figure 8 below is a graphic presentation of a summary of the illness notification that compelled the patients to seek medical attention.

These bodily notifications represent the start of biographical disruptions that the women experienced as a result of cervical cancer. These symptoms were disruptions to their physical body. Four of the respondents saw the initial symptoms of the disease as a sign of aging and menopause. They thought that the heavy bleeding they were experiencing was part of the effects of menopause or they were experiencing another phase of menstruation in their old age. They therefore saw the condition as normal or not life threatening enough for them to take any action.

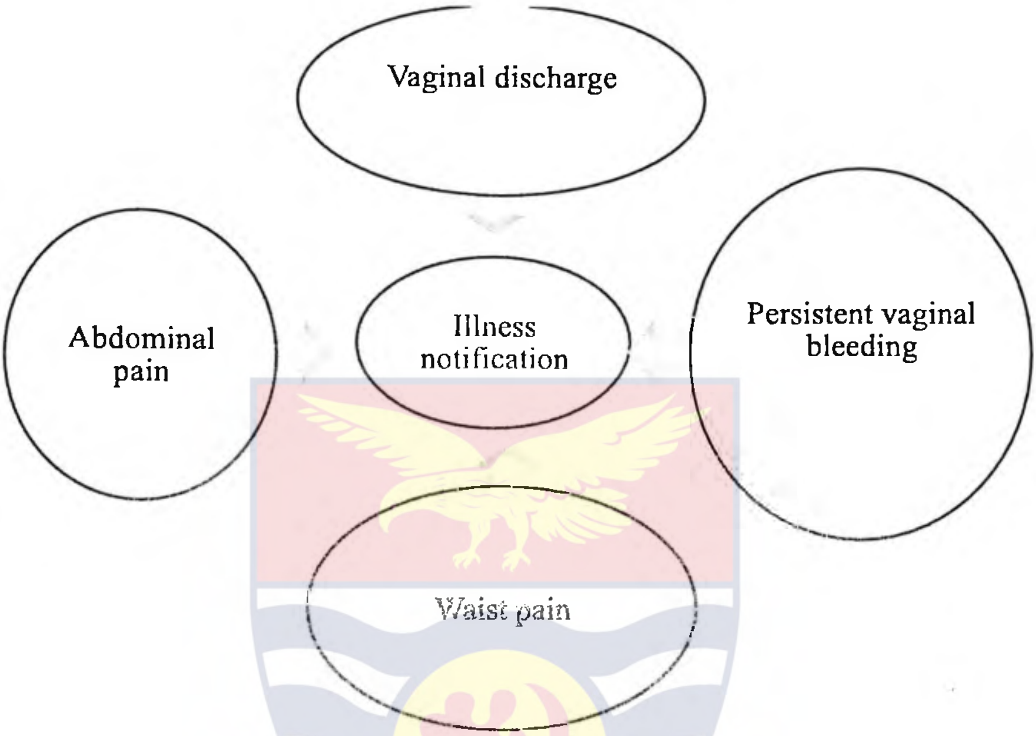


Figure 8: Thematic Network of Illness Notification

Frequent Vaginal Bleeding

Frequent vaginal bleeding was the dominant symptom identified by the women. The responses fell under two groups: (1) bleeding and changes in menstrual cycle and (2) bleeding after sex. All the 15 respondents cited bleeding as the first sign of cervical cancer. One of the respondents said she bled continuously for weeks, while 10 said they bled persistently. Two of the women said they saw clots of blood in their underwear and had to use sanitary towels, which they had to change frequently. Thus, both women who were in their menopause and the women who were younger, experienced some form of bleeding as a way of illness notification.

> *"Whenever I was about to have my period for the month, I bled for about one to two weeks. But I realised it did not take long for a new flow to start. I began having my period every two weeks and within a month, I would bleed twice. Then after the two weeks, I will start bleeding again for another two weeks. So I was wondering what was wrong. I was complaining now and then and then I started visiting government hospitals at Oda, Swedru, Jubilee, and Boafo. I visited all these hospitals."* (CCP1, 34 years).

Another said:

> *"One morning, I went to toilet and then I saw a blood stain in the toilet roll I used. I became frightened because I was about 59 years and I had my last menstruation when I was 46. So, I became suspicious that it was not menstruation."* (CCP 6, 63 years).

Four respondents also reported bleeding after sex as a sign of cervical cancer. Seven women reported that they bled after sex with their partners. According to them, the bleeding was not as result of sexual abuse because some even enjoyed the experience:

> *"With time I realised that I was bleeding after sex with my husband. Immediately after having sex with my husband, I always saw blood which I never understood and I was*

> *aggrieved about it because my husband never abused me"* (CCP 3, 43 years).

Sexual act, which was supposed to be an enjoyable activity, became an ordeal for the cervical cancer patients. The frustration of one of the cervical cancer patients is expressed below:

> *"Because of what is happening to me as a result of this condition, I don't have sex"* (CCP 14, 60 years).

Bodily Pains and Discomfort

Eleven of the cervical cancer patients said bodily pain was one of the early signs they had about the disease, but did not take any action until they started bleeding. Five of them said they had waist pains, 4 had abdominal pains and 4 could not walk properly, while some had swollen knees. Two of the respondents revealed the following.

> *"I had severe pains in my left leg, then it came to my waist so I took paracetamol which relieved me of the pains for some few moments. But when I woke the blood started flowing heavily at once then I was rushed to the hospital"* (CCP 14. 60 years).

The second respondent said:

> *"I had severe pains in my left leg then it came to my waist. From my waist down to my left side of my abdomen, I felt pains in there."* (CCP 15, 60 years).

Five of the respondents mentioned nausea, headache, dizziness and diarrhoea as some of the symptoms that preceded the heavy and persistent bleeding. Two of the respondents shared their experiences:

> *"I felt like vomiting so I relied on antacid powder so after eating and I took some antacid powder I didn't feel easy in my stomach too. I also felt a little headache, a little nausea"* (CPP 6, 63 years).

Another respondent also said:

> *"I couldn't eat, I couldn't t feel the taste of anything and was going to toilet frequently. I was very week and had to sleep a lot"* (CCP 2, 52 years).

Vaginal Discharge

Another sign respondents noticed at the start of cervical cancer was vaginal discharge. Five of the women reported watery fluids from their vagina, and were able to distinguish these fluids from "normal" vaginal fluids. Two respondents shared their experiences:

> *"I got to know that I had bad odour from my vagina. I smelt bad whenever I passed out urine and also whenever I went to ease myself".* (CCP 8, 62 years).

The other respondent also said:

> *"Before the condition started I began to experience vaginal discharges similar to discharges exchanged after sex"* (CCP 3, 43 years).

Illness Experience and Biographical Disruption

The combination of pain, vaginal discharge and excessive bleeding the women experienced marked the beginning of the disruption in their bodies and daily lives. The women experienced disruption at four levels: emotional, physical, psychological, economic and social levels.

Physical and Emotional Disruption

During treatment, most of the women reported body pains, cessation of sexual activity, loss of appetite, immobility and loss of sleep (Table 5). All the respondents said the pains they experienced in their vagina, waist, and entire body disrupted their lives. Five of the cervical cancer patients reported that they were so severe that they had to be given injections to reduce them.

Table 5: Physical Disruption Experienced by Women

Issue	Explanation
Body pains	Uncomfortable feeling in the lower abdomen
No sex	Pain during sex
Loss of appetite	Unwell, stressed, inability to eat
Immobility	Inability to walk around like any other normal human beings due to incessant bleeding
Loss of sleep	Inability to sleep due to bodily pains

Source: Fieldwork, 2014

A respondent throws more light on the condition:

> *"I felt some pains in my vagina and the doctor instructed that I should be given injection to reduce the pains. I was always in pain, my leg, everything, every part."* (CCP 11, 55 years)

Another physical disruption the respondents experienced was in their sexual life. Four of the cervical cancer patients reported that, because they bled and felt pains during sex, they had stopped engaging in sexual activity:

> *"I bled from the vagina anytime I had sexual intercourse. So I decided not to get myself involved in any."* (CCP 4, 44 years).

Three respondents reported loss of appetite due to cervical cancer. Two of the women could not eat well while one had no interest in food. According to them, food smelt bad and was tasteless. The act of eating was seen as a burden.

Another physical disruption the respondents experienced was their inability to move around. This was due to a number of reasons, including excessive bleeding, pain in various parts of the body and intake of various medications. For instance, three cervical cancer patients said they were afraid to go out of their homes because they feared bleeding and soiling themselves in public. Some of the women could also not walk because they felt pains in their legs and body. According to seven of the women, the drugs they were given made them immobile. The drugs made them dizzy and prevented them from walking.

> *"I felt lots of pain in my legs. I could not walk. The drugs given to me at Korle-Bu also weakened me and I could not do anything."* (CCP 8, 62 years).

Another said:

> *"I started experiencing waist pains so whenever I experienced the pains I visited the doctor for medications. Then my knees become swollen and it was bandaged. At a point I couldn't walk"* (CCP 11, 55 years).

The cervical cancer patients also reported loss of sleep as disruption they experienced due to cervical cancer. Six of the respondents said they could not sleep at all while others had to wake up intermittently to change their sanitary towels. Due to the pains and bleeding during sex, 9 respondents reported that they had to stop having sex even though they were married.

> "*I do not have sex and he also hasn't complained. I am frightened that if I engage in any sexual activity I might that start bleeding so I have even taken it off from my mind*" (CCP 14, 60 years).

Psychological Disruption

The women experienced psychological disruption at four levels: when they saw the disease symptoms, when they received diagnosis, during treatment and after treatment (Table 6). These disruptions were clustered into three areas: negative emotions, fear of death, and thinking.

According to three patients, when they noticed the symptoms of the disease, they became sad and fearful. They were afraid of the blood they constantly saw in their underwear and wondered what could have been happening to them. Some of the cervical cancer patients also felt sad and embarrassed about the situation.

Diagnosis was the stage when the patients experienced psychological disruption. The respondents reported worry, anguish, desperation and loss of hope. For some of them, they knew that cervical cancer was a deadly disease, and thought they were going to die. One woman experienced psychological disruption because she was hoping that her condition was fibroid and not cervical cancer.

Table 6: Psychological Disruption Experienced by Cervical Cancer Patients

Issue	Explanation
Negative emotions	Sadness, self-disgust, worry, desperation, bad feeling, confusion, loss of hope, isolated, tears and trauma.
Fear	Fear of the future, fear of death, scared, fear of the unknown, treatment efficacy, fear of cost of treatment, fear of recurrence.
Thinking	Thinking about life after treatment

Source: Fieldwork, 2014

The following were the explanations of two respondents:

> *"I was not very happy, but I gathered courage and raised my two hands and told God that, as for cancer it is death, so I do not want to die. Save me so that I can continue doing my work. I prayed in my head but I raised my hand in front of the doctor, then he said: aunty Bertha you would not die, it is better we have detected this early. And that is the day I realised that I have got cervical cancer."* (CCP 6, 63 years).

> *"I felt sad, because of the cancer. I thought I would just be operated only on the fibroid."* (CCP 9, 49 years).

According to some of the respondents, they started thinking about the disease after they had been diagnosed. Their thoughts were focused on why such a thing had happened to them and how they were going to bear the cost of treatment. According to two respondents, sometimes, they thought about the situation so much that even when others were speaking to them, they could not hear.

> *"I kept thinking, about the disease. Why should a young lady like me have this disease? What am I going to do now? Can I even pay? Sometimes, I do not even hear when people call my name".* (CCP 1, 34 years).

During treatment, the cervical cancer patients also experienced psychological disruption. Three of the respondents said that, in addition to the pains, they had bad feelings and cried. They were scared of the treatment methods, the potential results and side effects. One woman mentioned that when she was taken to the theatre and she saw the numerous knifes and machines that were going to be used, she became sad and begun to cry. Some of them also saw the CT scan as a coffin and this traumatised them and increased their fear of death.

> *"The doctor said that it will be very difficult for them to operate, so I should take it to Korle-Bu. They had the requisite machine for me to be treated. So, I decided to go to Korle-Bu and indeed it was true. They made me have series of laboratory tests and scanning, and thereafter, I was made to sleep under a*

machine. When I got there, it was scary, it was like a coffin."

(CCP 8, 62 years).

The women experienced psychological disruption after treatment. The women were afraid that the disease might recur. According to four of the women, they prayed that the pain and trouble they had experienced was enough and that the disease should not recur.

In a summary, it could be deduced that the cervical cancer patients experienced negative emotions and experiences at four levels; namely, the symptoms, diagnosis, treatment, and post-treatment. Therefore, the women constructed cervical cancer as a disease that has a never-ending psychological disruption once it commences.

Economic Disruption

The cervical cancer patients also experienced economic disruption in the following ways: cannot work, reduction in income, medical bills, loss of asset and indebtedness. The economic disruption was experienced during treatment (Figure 9). Ten of the cervical cancer patients reported that they could not work because they were in pain, they had to go to hospital or they had to fold up their businesses as there was nobody to take over. For even those who handed over their business to others, the people could not manage the business well for them. For example, there were two women who could not harvest their farm produce because they were on admission (CCP 5 and CCP 7). As a result, most of the respondents were not able to manage their businesses. For instance, one respondent lamented:

> *"All my work collapsed because I cannot do it on my own. Now, I can no longer work actively and my walking is also not as fast as it used to be."* (CCP 15, 60 years).

Due to their inability to engage in active work as was formerly the case, their income stream was disrupted; yet, they had to pay healthcare bills. The women reported spending between GHC 300.00 and GHC 10, 000.00 for treatment.

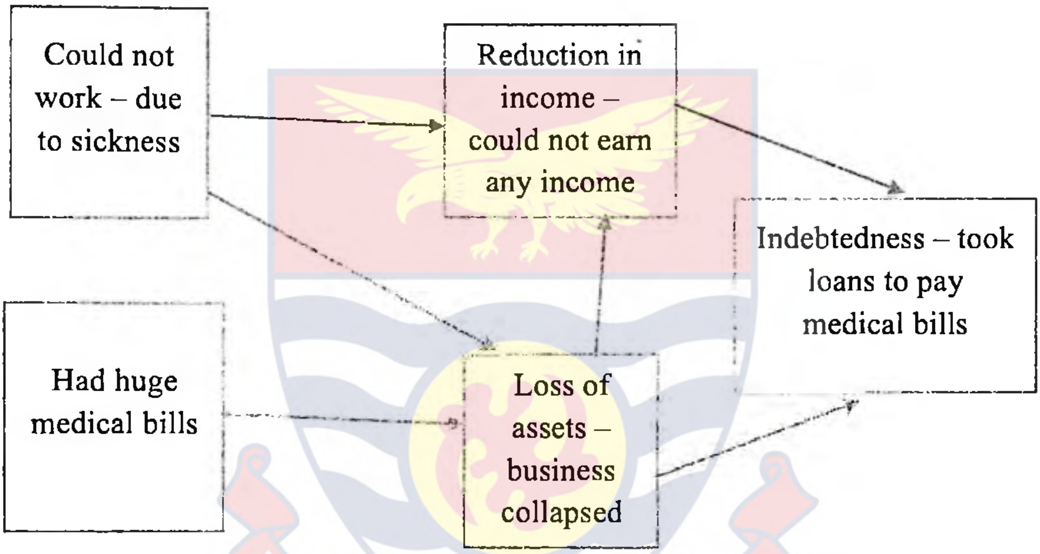


Figure 9: Economic Disruptions Experienced by Patients due to Cervical Cancer

Source: Author's Construct (2014).

As a result of the expensive medical bills, three women sold their assets and ten women took loans. For three of those who sold their assets (CCP 1, land; CCP 13, house; and CCP 7, cloth), they complained about a loss as they sold for less than these assets had been purchased. Two respondents explained:

> *"I could not calculate, which I do not think you should put on book, it will make you get sick. It is expensive to treat"*. (CCP 2, 52 years).

> *"I was so sick I could not work, but I needed money to pay for my bills. So I sold my land. It was a difficult decision but I had to take it. Unfortunately, the buyer noticed that I needed the money so he offered me less than the market price."* (CCP1, 34 years).

Five of the 15 respondents took loans to take care of their health. The respondents borrowed between GHC1000.00 and GHC6, 000.00. They took loans from both formal (banks and microfinance) and informal source (friends and relatives). For those who took loans from microfinance institutions they had to pay about 40 per cent interest. One woman had to take loans to pay back the loan she took from a microfinance institution.

> *"It is now left with the money, the places we borrowed from, we had to work to pay back these loans, so we are still paying them in bits."* (CCP 1, 34 years).

Cervical cancer brought economic disruption to the patients. The women lost their jobs, and had a reduction in income. Yet they had expensive medical bills to pay. As a result they sold their assets and took loans with huge servicing costs and as a result, the women became indebted.

Social Disruption due to Cervical Cancer

Break-up of social relationships was the dominant social disruption experienced by the respondents. Three of the women were deserted by their partners, while one of them had a strained relationship with her brother. The respondents said their partners left them because the women could not offer sex. The respondents said they felt disappointed as they were left without emotional and financial support during their treatment.

> *"Because of the disease, my husband went to marry another woman and left me. The infection of the disease made him leave me for someone else."* (CCP 4, 44 years).

Another respondent also reported strained relationship with her brother because of cervical cancer. The brother felt that he was spending too much money on her and as a result decided to abandon her. She explained:

> *"None of my family members will support, even my own sibling who comes after me did not mind me anymore. We went to Cape Coast and he said he had spent five times already. So he would not spend money to take care of me again because my mother and my father did not leave him any inheritance, which he can fall on to cure my disease. So I should not come to him again."* (CCP11, 55 years).

Discussion

The Health Belief Model (HBM) helped to explain how the lack of appreciation of the severity of cervical cancer prevented the sufferers from taking action to prevent or treat the condition (Glanz et al, 2002). The study found that all the respondents did not know about the disease before and even after diagnosis. They lacked knowledge about the causes of the disease, the population at risk, prevention methods and treatment modalities. For those who had an idea about the disease, the risk factors mentioned were, women who had ever given birth and all women being at risk of the disease. Some of the respondents also mentioned poor vaginal practices, indiscriminate sex and childbearing as causes of the disease.

The low level of knowledge about cervical cancer among respondents has been reported in other studies. Studies by Francis et al. (2011), Ndikom and Ofi (2012), Abiodun et al. (2014) and Williams (2014) on knowledge, perceptions and predictors of uptake of cervical cancer screening have reported little or no awareness about the disease among patients before they were diagnosed. This limited knowledge of the cervical cancer disease may be as a result of low or lack of intensive education or sensitisation on the disease among women in Ghana (Abotchie & Shokar, 2009).

Low level of knowledge about the disease leads to low uptake of screening services (Abiodun et al, 2014), which results in late identification of the disease and delay in seeking treatment. The interpretations the respondents gave to the symptoms showed their lack of understanding of what was happening to them. They could not understand the symptoms with cervical cancer because they lacked knowledge of the disease (Amoateng & Williams, 2012).

The respondents associated cervical cancer symptoms with aging and menopause. Their inability to associate the symptoms of cervical cancer could be considered as natural since most of them were aged above forty and menopause coincides with this age. Respondents in the current study mentioned health workers and the media as the two dominant sources for cervical cancer knowledge. Previous studies show that the knowledge and professional expertise of doctors are utilised by Ghanaians who seek health (Abanilla et al, 2011; de-Graft Aikins, 2005; de-Graft Aikins et al, 2012).

The biographical disruption concept helped to explain how living with a chronic disease such as cervical cancer could be debilitating and disempowering. The respondents experienced persistent bleeding, bodily pains, bodily discomfort and vaginal discharge, with some experiencing multiple bodily symptoms. Since most of the women did not know about cervical cancer before they were diagnosed, the changes they experienced made them suspect that something was not right with them. Other studies have suggested that a subjective experience through the process of ‘body-listening’ shape disease notification and experience (de-Graft Aikins et al., 2012).

The respondents also experienced biographical disruption as a result of cervical cancer. The women experienced physical, psychological, economic and social disruption as a result of cervical cancer. Research indicates that chronic illness has been considered as an entry into a new social arena (Bury, 1982). The initiation into the cervical cancer experience could explain the disruption the women encountered.

Psychological disruption, for example, was experienced because people found themselves in a situation of uncertainty, where they may have little or no idea of what was happening to them (Bury, 1982; de-Graft Aikins, 2005). Among persons living with diabetes, it was reported that some of them were unsure about whether and how to disclose their health condition to their relatives (de-Graft Aikins, 2005). Also, the uncertain knowledge about the impact and cause of the disease as well as appropriate behaviour in the face of complications have been reported to cause stress among persons living with chronic diseases (Atobrah, 2012; Domfeh et al., 2008).

The social lives of the cervical cancer patients were disrupted due to break up of relationships and deterioration in health. Some of the break ups were due to inability of the cervical cancer patients to have sex with their partners.

Other studies have reported similar findings about breakup of social relationships as a result of illness (Domfeh et al., 2008; Erwin et al., 2010; Ezechi, Gab-okafor, Ostergren, & Pettersson, 2013). For example, some relatives of cervical cancer patients stopped providing assistance as a result of the high burden of care they experienced in providing the assistance (Atobrah, 2012).

Conclusion

This study showed that the patients had inadequate knowledge of cervical cancer prior to their diagnosis. Interventions should, therefore, include health education from health experts to enhance understanding of cervical cancer. The education programme can focus on causes, symptoms and preventive behaviours through screening since it has the most impact on early detection and treatment of cervical cancer as suggested by Adanu et al. (2010) and Jemal & Desantis, (2010).

The physical, social, economic and psychological disruptions that the cervical cancer patients experienced could have implications for seeking treatment. These issues could be built into counselling sessions with patients in order to improve their knowledge of the disease.

CHAPTER SIX

COPING STRATEGIES AND HEALTH SEEKING BEHAVIOUR OF CERVICAL CANCER PATIENTS

Introduction

Coping strategies are the specific efforts, thoughts and behaviours used to manage the internal and external demands of situations that are appraised as stressful (Folkman & Moskowitz, 2004; Taylor & Stanton, 2007). Research has identified two types of coping strategies used by people to moderate their stressful events, namely active coping strategies and avoidant coping strategies. Active coping strategies are behavioural or psychological responses designed to change the nature of the stressor itself or how one thinks about it. Avoidant coping strategies on the other hand, influence people into activities (such as alcohol use) or mental states (such as withdrawal) that keep them from directly addressing their stressful events (Folkman & Moskowitz, 2004; Feder, Nestler, Westphal, & Charney, 2010).

Generally, people adapt to situations to alleviate stressful circumstances, or to regulate the emotional consequences of stressful or potentially stressful events such as cervical cancer. Research has established that how people cope with stressful events influence their psychological, physical and social wellbeing (Šprah, & Šoštarič, 2004; Stanton, 2010).

This chapter presents the findings based on objective two of the study, which deals with the coping strategies adopted by the 15 cancer patients after diagnosis and their health seeking behaviour. These coping strategies include psychological and personal coping strategies as well as social support. The Socio-ecological Model was applied in exploring the different levels from which the respondents received support, and the different health-seeking pathways they adopted to cope with the disease.

Coping Strategies Adopted

A summary of the strategies adopted by the patients is presented in Table 7. There was a sequence to the way in which they coped with the condition. After diagnosis, the cervical cancer patients disclosed their condition to someone they trust, sought healthcare (biomedical, herbal and faith healing) and adhered to medication. Nine out of the 15 respondents said they disclosed their status to their husbands. Ten of the respondents relied on prayers while two respondents said they tried to ignore the sickness by pretending all was well with them. All the respondents sought medical help when they started bleeding heavily when other methods, such as prayers and herbal medicine, failed to solve their health problems.

Table 7: Coping Strategies Adopted by Patients

Category	Explanation of coping strategies
Personal	Abstinence from sex, observing personal hygiene and pretending they were not sick
Support	Financial, social, emotional and non-material support
Health seeking behaviour	Faith healing, orthodox medicine, Herbal medicine,

Source: Fieldwork (2014)

Personal Coping Strategies

The respondents adopted three active personal coping strategies: abstinence from sex, personal hygiene and pretending they were not sick (denial). From the interviews, 9 of the respondents reported that they withdrew from sexual activity due to bleeding after sex. The respondents explained that they were actively engaged in sexual activity before the diagnosis but had to decide with their partners to abstain from sexual intercourse in order to stop the blood flow and reduce the pains they were experiencing. Two of respondents shared their experiences:

> *"With the treatment (cervical cancer treatment), it had not equally been easy having sex. Cancer comes with painful sores; so until the treatment is completed and the sores are healed, I had to abstain from sex"* (CCP 2, 52 years).

Another respondent also explained:

> *"After going through the treatment process (cervical cancer treatment), I was frightened that if I engage in any sexual activity, I might start bleeding. So I had even taken sex off my mind"*. (CCP 14, 60 years).

Respondents also adopted some personal hygiene mechanisms. The first personal hygiene strategy adopted by the respondents was the frequent use of sanitary pads and rags to stop leaking blood. In the interview, a woman responded:

> *"Just like how we usually use the sanitary pads during our menstrual period, that was how I managed myself. So that*

> *whenever I went out to a place or sat at a public place, I would not soil myself".* (CCP 1, 34 years).

Three of the respondents said they used detergent to prevent bad odour from the vaginal discharge and blood flow. Two respondents reported they added disinfectants such as Dettol to water to clean themselves and their vagina. The respondents explained that they thought that using disinfectants to clean their vagina would kill the germs and bacteria they might had attracted from the environment due to the blood.

> *"After bathing, I drop some Dettol (disinfectant) in water and cleanse my vagina with it. Then I use a pad. I keep changing the pad from time to time so that I do not soil myself."* (CCP 11, 55 years).

Denial of the existence of the disease was also observed as a coping mechanism. The experiences of the respondents showed that living with a chronic disease such as cervical cancer is a stressful event that requires using psychological coping strategies to manage the condition. Two of the respondents, as a way of coping with the disease, chose to deny the existence of the condition. They explain:

> *"For coping, I always tried to forget about the condition (cervical cancer) and then hoped I was healed"* (CCP 6, 63 years).

> *"If I focus my mind on this disease, I will die so I do not even think about it. For me, it is one day at a time"* (CCP 14, 60 years).

In order to cope with the condition, one respondent said she had to make conscious efforts to keep her emotions in check to try as much as possible to remain calm in the midst of the pain and excessive blood flow. This reflects in her statement:

"To cope, I tried to handle the situation calmly" (CCP 9, 49 years)

To her, handling the situation calmly would help prevent the condition from worsening and facilitate her healing process.

Support

Respondents were asked the types of support they received after the diagnosis of the disease. Respondents identified three main types of support: social, financial and non-material support (Table 8).

Table 8: Support Received by Respondents

Type	Nature	Source
Social	Talked to others, prayed for, run errands for her, was assisted with intake of medication	Church, spouse, children, friends
Financial	Monetary donations, payment of bills, transportation fare, personal expenses	Spouse, siblings, children
Non-material support	Cooking, washing of dishes and clothes, housekeeping, business support	Children, siblings, friends

Source: Fieldwork 2014

Social Support Received

All the cervical cancer patients received one form of support or the other to cope with the disease. These include emotional support from the religious leaders, spouses, church members, children, friends and ethnic associations. Five of the respondents reported that during prayer meetings at church, they were called to the front and prayed for by their church leaders and members. One woman, who did not know which church to attend for spiritual help, was assisted by her friend to identify which church to attend. The following were the responses of some respondents:

> *"My friends and church members were also helping me with prayers"* (CCP 4, 44 years).
>
> *"My partner, he was just praying. My children were also praying for me."* (CCP 12, 58 years).

According to the respondents, they felt restored, revived and full of hope after they had been prayed for. Five of the women believed that without the prayers they received, they could not have survived the treatment and the constant fear of death. Some respondents also believed that they had support because the providers did not want them to die and some supported because they felt it was their obligation to provide support. The following describes the experiences of a respondent:

> *"My children, my sister's children and my sister, they all treated me well. They did not want me to be depressed about the condition because they thought I may die out of depression.* (CCP 5, 50 years).

One respondent also reported the social support she received during the treatment process. Her sister always escorted her to the hospital and helped her do the rounds at the health facility. This is reflected in the following response:

> *"Anytime I was visiting the hospital, my sister always accompanied me. She did all the queuing and rounds the nurses wanted me to do and help me take my medication. I could not walk, so she really saved me."* (CPP 5, 50 years).

According to the respondents, social support was one of the reasons they had been able to cope with the disease and that it had facilitated the healing process.

Financial Support

Due to the cost of treatment and the inability of the cervical cancer patients to work during treatment, they had to rely on financial support from others. According to some respondents, they received financial support from their children, parents, other relatives, church members, spouses, spouse relatives, friends as well as neighbours. For two of the women, their children paid their hospital bills, which were between GHS300.00 and GHS2000.00. The following were the responses of some respondents:

> *"My husband was helping me in financial aspect and the children and family also helped."* (CCP 8, 62 years).

Nine of the respondents had financial support from their siblings and children whenever they had to go for treatment and any medical check-up. This has given them a boost during the treatment process of the disease:

> *"For the financial aspect, I was assisted by my sister and children. They paid my bills for me and even gave me some money to live on when I was in the hospital. They spent close to GHS2000.00 on me"* (CCP 4, 44 years).

Non-material Support

Eight out of the 15 cervical cancer patients recounted receiving some non-material support services, including washing and cooking from their children, relatives, spouse relatives, formal caregivers, friends and self-help. These relatives cooked for them, washed their clothes and cleaned their homes while they were at the hospital. These were the responses of some respondents:

> *"When I came here, I was told there are people who cater for patients for a fee, so my child gave one of those people money. They requested five hundred (500 GH cedis) which she paid. Every now and then, they will come for money to buy me food. When my things get dirty, they will wash for me"* (CCP 11, 55 years).
>
> *"And in terms of washing, cleaning, cooking, I was assisted by my relatives and husband's relatives"* (CCP 13, 47 years).

Health Seeking Behaviour after Diagnosis

Health seeking behaviour refers to a "sequence of remedial actions that individuals take to rectify perceived ill-health" (Mahmood, Iqbal, & Hanifi, 2009). Health seeking behaviour differs from one individual to another.

Respondents engaged in various health seeking behaviours, including seeking remedies from orthodox medicine, herbal medicine, faith healing and self-medication (Figure 10). Four of the respondents said they combined prayers with self-medication but had to go to the hospital when they started bleeding heavily. A respondent explains:

> *"I gave my life to God and knew that he will heal me. When I realized the sickness in the house, I didn't do anything. However, I was also buying any drug I thought could heal me. But when I started bleeding heavily, I had to agree to go to the hospital"* (CCP4, 44 years).

Six of the respondents said the combination of prayers and orthodox medicine worked for them. This was captured by a respondent:

> *"When you are sick you have to go to the hospital before you can then add prayers to it. I didn't seek any traditional medicine. I came to the hospital first before I sought spiritual help through prayers"* (CCP 14, 60 years).

Three of the respondents said they started with herbal medicine first but had to go to the hospital when they started bleeding excessively. A respondent recounted her experience:

> "*Sometime I bleed in my underwear. It continued till one day I realized a big blood clot came out from my vagina. When that happened, I noticed pain in my thigh so I decided to take some herbal drugs"* (CCP 7, 59 years).

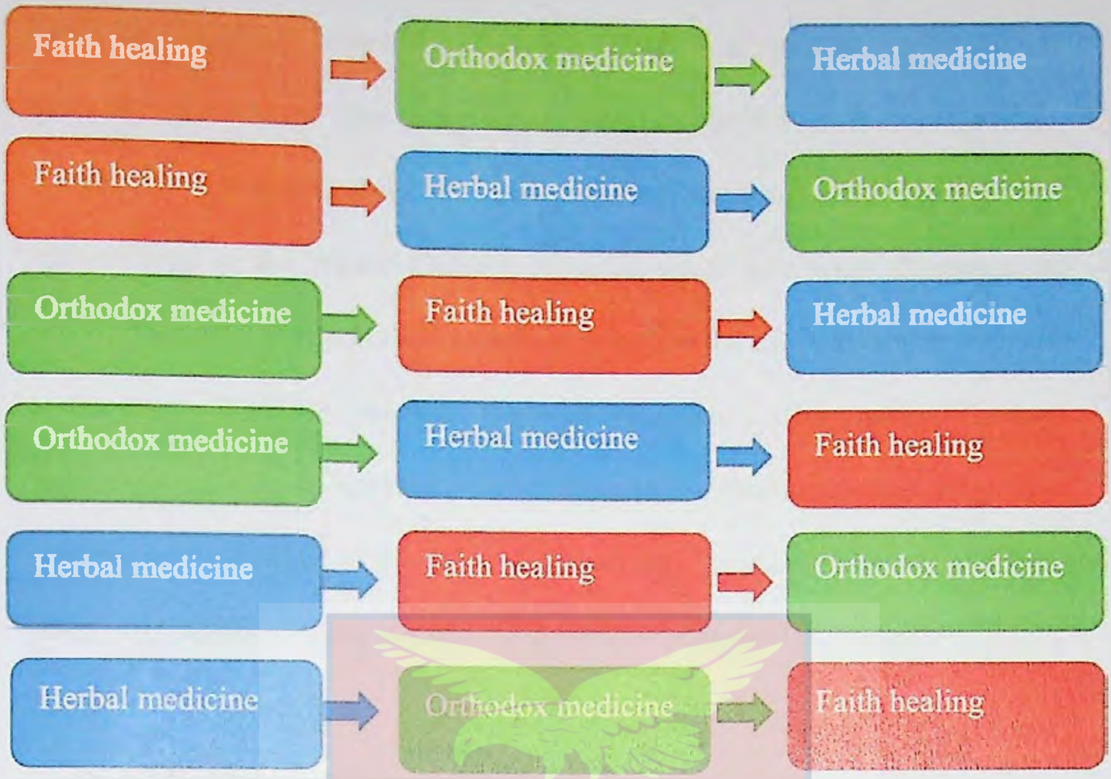


Figure 10: Health Seeking Pathways of Cervical Cancer Patients

There was also the use of a combination of orthodox medicine, faith healing and then herbal medicine. Orthodox medicine, however, became the last resort when complications set in. In spite of the efficacy of orthodox medicine, 10 of the respondents felt the ultimate healing came from God. A respondent confirms this:

> *"With cancer you can't just treat it like that. You have to treat it with God because God is the healer. It is the grace of God because at the hospital it wasn't easy at all"* (CCP 2, 52 years).

Orthodox Medicine

All the women had used orthodox medicine after diagnosis. They sought treatment from public hospitals such as Battor Catholic Hospital, Korle-Bu Teaching Hospital and Ridge Hospital as well as some private hospitals. Twelve of the respondents were diagnosed at Battor Catholic Hospital. One respondent was diagnosed at the Volta Regional Hospital at Ho and referred to the Battor Catholic Hospital while two were diagnosed at private facilities. Surgery was conducted for 12 of the cervical cancer patients at the Battor Catholic Hospital. Three of the patients who required therapy were then referred to Korle-Bu Teaching hospital. During the treatment, the women were admitted to the hospital for periods between one week and four weeks. A summary of the reported treatments is presented in Table 9.

Table 9: Treatments Patients Received

Treatment	Type
Therapy	Radiotherapy, CT Scan, chemotherapy, brachytherapy,
Drug	IV fluids, injections, tablets
Surgery	Uterus removed
Review	Frequent check-up

Source: Fieldwork 2014

The 15 cervical cancer patients were given drugs in the form of injections, IV fluids and tablets. Six of them had undergone surgery. Three had a complete removal of their uterus and the other three had the cancerous sections removed.

> *"The doctor told me that the womb would be removed through operation. They will pull the womb. They would fold my womb*

> *and cut it and I will come and sleep in the hospital for one week so, I went and they did it for me."* (CCP 6, 63 years).

Three of the cervical cancer patients went through either chemotherapy, brachytherapy or radiotherapy and had the following to say:

> *"When I came, I was asked to lie on a machine, I had to lie in the machine for three or six weeks. I cannot exactly recall the number of weeks. I lay in the machine for some time and I was asked to take an injection.* (CCP 14, 60 years).

> *"I did radiotherapy and chemotherapy. Finally, we had to go for brachytherapy at Korle-Bu. The doctor said it will kill the cancer and I will be free."* (CCP 2, 52 years).

The women went for frequent reviews to monitor the progress of the treatment they were receiving. Some of them visited the clinic every month, every two weeks and every other month:

> *"After the operation, they had cleaned the place for me and after the sore is dead, I had to go for review. I was going for review every month. I had to go for review so that the doctor will see that everything is good and that I am actually doing well".* (CCP 12, 58 years).

The respondents accepted orthodox medicine because they believed that it was essential for their survival. Apart from symptoms such as pains, profuse, vaginal discharge, vaginal smell and paleness, they got scared at the sight of heavy bleeding with clots, which they thought was a sign of death. In that state of helplessness, they were compelled to go to the hospital. A respondent explains:

> *"I was scared. I had no choice but to go to the hospital. In the hospital, you are examined. And then the doctors, nurses, equipment for examinations are available in the hospital. The laboratory is also in the hospital. We have a lot of things in the hospital that will cater for your health. For these reasons, I felt the hospital is the best place."* (CCP 6, 63 years).

Herbal Medicine

Seven of the respondents reported using herbal medicine. They explained that they used herbal medicine because they felt that orthodox medicine had or may have failed them. They used the herbal medicine to manage or stop the blood flow and relieve the pain they experienced. The respondents obtained local herbs, Chinese medicine or food supplements (such as aloe vera, ginger, moringa, dandelion, and garlic). Two women combined local herbs (leaves, soap), Chinese medicine and food supplements.

> *"I went to the hospital, but unfortunately the bleeding became worse, so I started looking for local medicines."* (CCP 2, 52 years).

With the exception of one respondent who was given soap, all the respondents did not know the medicine they were given. Some of them described it as homemade products from roots, barks and leaves of trees. Some of the products were rubbed on the stomach and others were taken as syrups or tablets. They believed that the drugs were effective since the blood flow eventually stopped. However, some of the women reported complications:

> *"Yes!, the last time, I bought a soap which I had to use by rubbing it on my stomach. But the blood flow became worse. I was bleeding heavily than normal."* (CCP 8, 62 years).

One respondent was offered herbal medicine by a friend but she feared complications and did not use them and some of those who had used herbal medicine experienced deteriorating conditions and had to stop.

Faith Healing

Ten out of the 15 respondents said they relied on prayers. Five of them said they sought treatment from faith healers. According to them, it was God who heals. Those who went to church to seek divine intervention had hands laid on them or given anointing oil and holy water to drink.

> *"In fact, from the theatre, I was on the bed and I was looking at everybody. I was unable to talk. My relatives were there, so when I saw them I became happy. The first thing I did after my operation was that, I put my hand around my stomach and I saw a plaster, then I told myself God has done it. So, after feeling the plaster, that joy in me lingered on, so that was it. In fact, when you believe that you are healed and you are not thinking of negative things the healing becomes faster."* (CCP 6, 63 years).

According to them, they needed special prayers in addition to orthodox medical treatment for the healing process to be complete. The respondents considered faith healing effective for curing the cancer and clearing it out of their system. One of them explained:

> *"I came back from prayers and the cancer was off. So this is how I went about the condition. I went the second time and it was all gone. So, really, with cancer you cannot just treat it like that. You have to treat it with God because God is the healer. That man, I knew very well is a healer. It is the grace of God because at the hospital it was not easy at all for me."* (CCP 2, 52 years).

Eight participants also reported that in times of emotional or physical difficulties, they resorted to religion or divine intervention. The respondents believed that if they turned to God, they would receive mercy and healing. As such, a patient had to travel to Nigeria to consult a man of God for healing. Another patient also decided to personally pray consistently for her healing.

> *"I decided to go to Nigeria and add prayers because God is the finisher of everything. So I went to Nigeria for prayers and God healed me"* (CCP 2, 52 years).
>
> *"I had to pray to God. I just prayed to God so that he can do everything for me. Sometimes, I would be praying and ask God not to let me die. Sometimes too, I would be dreaming after the prayers. That is all I do."* (CCP 12, 58 years).

Discussion

This chapter sought to analyse the coping strategies adopted by cervical cancer patients in managing their condition and their health seeking behaviour. The specific themes that emerged from the interviews included psychological coping strategies, personal coping strategies, and social support.

The respondents used faith healing, orthodox medicine and herbal medicine as treatment regimes.

The study results revealed that cervical cancer patients employed various active and avoidant strategies to cope with their condition. For instance, while seeking treatment, two of the cervical cancer patients tried not to dwell on their condition with the belief that this was the best way to manage the disease condition. Even though this may not be the best way to manage such a serious condition, the women believed that it was beneficial in seeing them through the treatment process. On the contrary, Mukwato et al. (2010) observed that, among breast cancer patients, positive attitude and suggestion as well as re-affirmations were some of the major coping mechanisms adopted. Others have also been found to resort to positive thinking and purposeful lifestyle as a coping mechanism (Ramanakumar et al., 2005).

Some cervical cancer patients used religion as a coping strategy. For instance, most of them believed that if they honestly believed in God, all their disease conditions would be solved. Consequently, some tried prayers and visiting ministers of the gospel for divine intervention. This is not unusual, since research has established that people use religion to cope with their health problems (Bediako, 2000; de-Graft Aikins, 2005). Mukwato et al. (2010) observed that reliance on God was one of the predominant mechanisms used by patients as well as their family members to manage difficult conditions such as breast cancer in Ghana and Zambia.

Furthermore, some of the respondents adopted abstinence from sexual intercourse throughout the treatment process to enable them to cope with their condition. Respondents indicated that to avoid worsening the disease condition and having a successful treatment, they had abstained from sexual intercourse with their male partners throughout the treatment process until their condition had improved. The implication of this was that it could encourage extra marital affairs on the part of the male partners.

The study also established that cervical cancer patients used sanitary products including sanitary pads, cloths as well as disinfectants to manage the effects of the condition. Some of the respondents also explained that using sanitary materials, together with disinfectants, made them feel secure and hygienic. As a result, they were more able to sit and take part in public activities than before.

It has been observed that family members are often important sources of support in times of difficulty (Fayorsey 1995 cited in Maxwell et al., 2000). Some cervical cancer patients were able to cope with the disease because of emotional, financial, physical and personal supports received from their partners. Other family members such as children, siblings, nieces and nephews provided some form of financial, social and emotional support as well. Ramanakumar et al. (2005) have alluded to the importance of support from other family members, friends as well as the community to be important for patients to cope with unpleasant situations. The women therefore reported that the various support provided by the different categories of people strengthened them in a number of ways and helped them to survive the disease.

The study also explored the health-seeking behaviour of the respondents. The respondents used faith healing, orthodox medicine and herbal medicine. The pluralistic use of these modes of healthcare has been observed in studies among Africans living with various chronic diseases (de-

Graft Aikins, 2005; Hjelm & Atwine, 2011; Kolling, Winkley, & von Deden, 2010). The respondents used these different modes of treatment without consulting their doctors. Most of the respondents used faith healing or combined it with orthodox medicine because they considered God as their source of healing and the ultimate healer. The women used traditional medicine and supplements as a complement to orthodox medicine.

The perceived effectiveness of herbal medicine by the women was mixed. While some reported improvement in their condition, some reported no change while others reported deterioration of their condition. Perhaps two factors could explain this behaviour. Firstly, the herbal treatment was without surgery and was not expensive, unlike orthodox medicine. Secondly, their decision could also be explained by the lack of understanding of what the disease was and its causes. There have been reports of the lack of medications for cervical cancer treatment at health facilities (Adanu et al., 2010; Willaims & Amoateng, 2012). In addition, the lack of improvement that women experienced after using orthodox medicine can also explain why they resorted to herbal medicine.

The health seeking behaviour adopted by the patients have implications for treatment and adherence. In particular, it has been found that the use of herbal medicine does not improve the destruction of cancerous cells and relieve the pain associated with cervical cancer (Ezechi et al., 2014). However, herbal medicine is found to play a major role in complications and high mortality among patients (Ramanakumar et al., 2005).

Conclusion

This chapter presented the coping strategies and health seeking behaviours adopted by women experiencing cervical cancer. The women adopted personal, psychological and social support systems to alleviate the challenges associated with cervical cancer. The cervical cancer patients used a combination of faith healing, herbal medicine and biomedical systems to treat their condition.

It seems that out of frustration, cervical cancer patients adopted inadequate and non-scientific approaches as a means of coping with the disease.

CHAPTER SEVEN

BARRIERS TO CERVICAL CANCER SCREENING AND TREATMENT

Introduction

Studies have identified a number of factors that constrain the uptake of cervical cancer screening and treatment. These may include economic, personal or psychological, socio-cultural, political and health system factors (Kelly et al., 2008; Reis et al., 2012). This chapter responds to objective three of study that examined the barriers to cervical cancer screening and treatment using the socio-ecological lens at the individual, institutional, community and policy levels (Daley et al., 2011).

Characteristics of Respondents

For the study, ten women who had never been screened for cervical cancer were interviewed. Five of them were between 30 and 39 years while another five were between 40 and 49 years. Four out of the ten had completed JHS/Middle school education while two had never been to school.

Five focus group discussions were held among both women and men; three for women and two for men. Thirty women took part in three focus group discussions of which fourteen of them were aged 40-49 years. A total of sixteen men participated in two focus group discussions. Eight of them were aged between 30 and 39 years and the majority had JHS/Middle education.

Barriers to Cervical Cancer Screening

Respondents were asked to identify and explain the factors that could prevent women from undergoing cervical cancer screening and treatment. The barriers were classified into individual, community, institutional and policy level factors as presented in Table 10.

Table 10: Summary of Barriers to Cervical Cancer Screening

Level	Barrier
Individual level	Low level of awareness of cervical cancer screening, psychological, economic barriers
Community level	Socio-cultural norms, gendered norms
Institutional level	Health workers' attitude, issues of confidentiality and privacy
Policy level	Lack of subsidy, unavailability of facility, low education

Source: Fieldwork 2014

Individual Level Factors

The individual level factors refer to beliefs, attitudes, past experiences and motivations that influence people's behaviour. Three barriers were mentioned in relation to cervical cancer screening: low awareness of cervical cancer screening, psychological and economic barriers.

Low Level of Awareness of Cervical Cancer Screening

Knowledge about the existence of cervical cancer and where one can obtain a screening service is important to the uptake of screening and treatment services. One barrier to the uptake of cervical cancer screening services was low awareness of the disease (Figure 11). Cervical cancer patients, for example, did not know about the disease, causes, symptoms and screening services before they were diagnosed.

Among the 10 women from the community who had never screened and did not have the disease, three reported that they did not know it was a type of disease. Twelve women from the focus group discussion also reported that they had never heard of cervical cancer. Among the men 16 focus group participants, 4 of them expressed surprise that such a disease existed and could kill women. One male discussant said:

> *"I have never heard of cervical cancer disease. Is it also a disease that affect women? Then women are suffering."*
>
> (MFGD 1).

This implies that the men had little or no knowledge of the disease. The implication of this is that men who had no knowledge of the disease would not encourage their women to go for screening. They may also likely not provide any support for their women even when the women decide to take the initiative to screen.

Psychological Barriers to Screening

Fear was the dominant psychological barrier identified from the interviews. Among respondents who had heard of the disease and screening services, the fear of testing positive caused them not to submit to screening. The fear was at three levels; (1) fear of death, (2) fear of being wrongly diagnosed and (3) fear of what to do if they were diagnosed positive. A woman who had never been screened before explained:

> "*For this condition, when you get it, you are going to die. So it is better I do not screen to know my status*". (WWHNS 2, 43 years).

Lack of appreciation for disease prevention also accounted for the unwillingness to screen among the female respondents in the Battor community, who attend the hospital. The following statements explain reflect the thoughts of some respondents:

> "*If you have pain in the vagina, then you will go to the hospital for that test. But if you do not feel any pain in your vagina, you should not be forced to go for the test (laughing)*" (FFGD 2).

Another respondent also responded:

> "*Why should I go to hospital if I am not sick? To do what?*" (WHNNS 5, 50 years).

To one of the female respondents, "*what you do not know, does not kill you.*" Thus, it was better not to screen for cervical cancer. As a result, these respondents did not seek screening services, as they were afraid of the condition because it was perceived as a deadly disease and positive test is equated to death. The following statement was made by one respondent who has never screened:

> *"I did not screen because I was afraid of the condition [cervical cancer]. For this condition, when you get it, you are going to die".* (WWHNS 2, 43 years).

The perception of the fatalistic nature of cervical cancer could be found in local words used to refer to the disease. Among the Ewe, the word used is *Abimakumaku* which means that a wound that can never heal and therefore would eventually "kill" the victim. Four of the female discussants said that the association of the disease with death causes fear in them, even without being diagnosed.

In the discussions, some respondents expressed fear of wrong diagnosis of the disease as a reason for not seeking cervical screening. According to participants from the FGD, it is possible that a hospital could wrongly diagnose them of having cervical cancer if the hospital did not have the appropriate equipment. They based the conclusion on previous experiences when they were treated for diseases they did not have. They, therefore, preferred not to know their status rather than being misdiagnosed.

> *"My life is better like this. The doctors can give you fake results, they do not have good machines to do the test and they will just scare you."* (WFGD 3).

Another respondent who had never been screened also explained her reason for not screening:

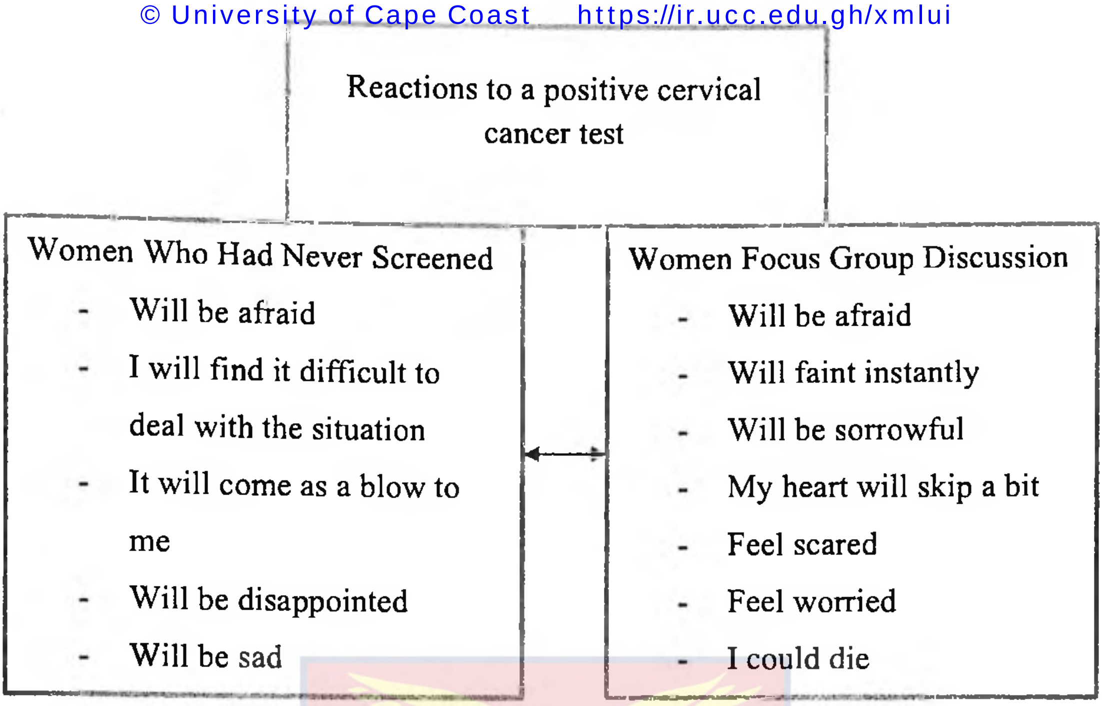
> *"I have told myself, I will never go for any screening program. This is because, one day I came to the hospital with my husband who was then sick and coughing. They ran a test to confirm it was tuberculosis. They advised that I come with all*

> *my children to be screened and it was done on our inner arm. I was then diagnosed with TB. Then on another occasion, one of my children was sick and we were all asked to screen and I was diagnosed with sickle cell disease. But I do not have sickle cell disease. Therefore, whenever they were enlisting people for any test, I decided not to go. Because, whenever I do the test, the results were frightening, which were not even true".* (WWHNS 2, 43 years).

Another reason why some female respondents did not screen was fear of life after testing positive. From the in-depth interviews, the women indicated worry and anxiety about what to do if they tested positive. They worried about treatment procedures, cost of treatment and cure. They were worried that they may never be cured if they tested positive. As a result of these concerns, the respondents chose not to seek screening services.

> "*I do not even know about this disease, so why should I bother to know my status. What will happen to me if I have it? Since it is cancer, it will be very expensive to treat. I do not even know if I will get better again should I be treated. So as for me, it is better you do not know."* (WWHNS 1, 34 years).

The fear attitude was also expressed in the interviews with the women who had never screened when they were asked about their reaction to a positive diagnosis (Figure 11). They mentioned that they would be afraid, faint instantly, be filled with sorrow, miss a heartbeat, think they would die, and be scared.



Reactions to a positive cervical cancer test

Women Who Had Never Screened
- Will be afraid
- I will find it difficult to deal with the situation
- It will come as a blow to me
- Will be disappointed
- Will be sad

Women Focus Group Discussion
- Will be afraid
- Will faint instantly
- Will be sorrowful
- My heart will skip a bit
- Feel scared
- Feel worried
- I could die

Figure 11: Reactions if Tested Positive for Cervical Cancer

Source: Fieldwork 2014

Economic Factors

During the discussion, the perceived cost of screening services was another individual factor that prevented women from seeking screening. From the in-depth interviews and focus group discussions, individuals expressed concern about the potential cost of screening services. Some of them perceived that the services may be expensive and they could not afford it. In estimating the cost of services, participants calculated transportation to the health facility, cost of health insurance and cost of the screening services:

> *"For now, I am not working. If I had strength to be working, I would have paid the required amount. There are some who had no money, transport fare or health insurance and because of that they could not go for screening".* (WWHNS 8, 41 years).

During the focus group discussion participants were asked for their desired cost of screening services. Some of the participants wanted the service to be free. Among persons who quoted a fee, the cost ranged between GHC1 and GHC50. Only one woman was willing to pay for "*whatever they charge.*"

According to three participants from the female focus group discussion, their level of income was low because they were subsistent farmers and that was why they wished the service was free. These women earned between GHC10.00 and GHC30.00 per week. Some of the female discussants, however, thought that they could afford the service if they should prioritize their health needs over other social responsibilities.

Six out the 15 cervical cancer patients, during interviews also identified cost of screening and treatment as a major barrier. They suggested that screening should be put on the National Health Insurance to encourage more women to go through screening. One respondent noted:

> "*If the government could help for national health to cover screening it will be very good for women*" (CCP 2, 52 years).

Another said:

> "*When we came here we were told that health insurance does not cover any of the cost so we ignored it. What I want government to do is to make health insurance cover all the cost involved*" (CCP 15, 60 years).

Community Level Barriers to Cervical Cancer Screening and Treatment

The study identified gender norms as one of the barriers to cervical cancer screening and treatment. The gendered norms included concerns about women exposing their nakedness to male doctors and the association of the disease with immorality.

Gendered Barriers to Cervical Cancer Screening

The respondents said social expectations as to how women are expected to behave prevented them from seeking screening services. The issues included concerns about exposure of the female genitalia to another man other than their male partners or husbands. Among the women, there were mixed feelings about this as some did not express worry exposing their genital to others, and others did not care whether the examiner was male or female. But others did care about the process and about whether it was conducted by a male or female health worker. Five out of the 10 female respondents in the in-depth interviews who have never been screened and 13 out of 30 women in the focus group discussions said they were uncomfortable with the process. One of the respondents said:

> *"That one is "shying", allowing someone who is not my husband or even my boyfriend to enter there [vagina] is something which must be stopped."* (WWHNS 10, 31 years).

Another said:

> *"For me, I feel shy to open that place to anybody...even a woman because that place is private to you and your husband, the doctors should find another test or they can use blood test."* (WWHNS 2, 43 years).

Some women also reported that they would be embarrassed no matter the physician's gender. Some women said they refused to go for screening because it involved exposing the genitalia to another person. Some respondents suggested that, to increase the number of women getting screened, it would be important to change the test from the present trans-vaginal screening to a less embarrassing procedure which would not involve exposing women's genitalia to a physician. Some respondents noted that:

> *"A lot of women feel shy. They know that they will be attended to by male doctors. They are not willing for male doctors to attend to their private parts".* (WFGD 2).

Most of the men in the focus group discussions, however, had no problem with male doctors examining their wives if it was to save life. One of the noted:

> *"Suppose there is only a male doctor available when a female patient is brought in. Will the male doctor refuse to attend to the female patient for her to die?"* (MFGD 1).

Another male discussant also noted:

> *"Supposing a women is going to deliver and there is no female doctor, the male doctor should not attend to her? No"* (MFGD 2).

The socio-cultural belief that cervical cancer can be caused by the promiscuous lifestyle of a woman emerged as a barrier to cervical cancer screening. Cervical cancer was considered a sexually transmitted disease. Three of the men in the focus group discussion attributed cervical cancer to sexual promiscuity. According to some, cervical cancer was punishment from the gods that is meant to punish women who are unfaithful to their partners.

The men, however, did not regard themselves as those responsible for transmitting the disease to women. One of the discussants said:

> *"You know we are flesh and blood, as we are males anything at all like sexual immorality can happen. But the women have to take care of themselves. It can be prevented if a woman will stay with one man, it can be prevented like that."* (MFGD 2).

This belief prevented women from seeking screening in two ways: (1) they felt that going for screening was a sign of a promiscuous lifestyle and (2) a positive test result was a confirmation of that lifestyle even if the person does not engage in such lifestyles.

> *"The way our men think, if you go to the hospital to test they may say you are seeing other men. And if you are unlucky and you have it, you are dead. Everybody will conclude that you have been sleeping around."* (WFGD 3).

Another barrier raised in both the in-depth interviews and focus group discussions was normative gender relations; where men assumed the role of decision makers even when it had to do with the health of women. These gender relations largely ascribed by some respondents showed that they needed the approval of their partners to undergo screening for cervical cancer. This follows from a statement made by a woman in the focus group discussion as follows:

> *"So you see, traditionally, no other man should touch the private parts of a married woman. So for us women, we need to get our husband's approval."* (FFGD 2).

According to the respondents, it was necessary to ask for consent from their husbands because some men feel jealous and do not want another man looking at their partner's private parts. The need for spousal approval resulting from normative gender relations was reflected in the following statements made by two respondents:

> *"For some of us who are in very remote areas, we have to seek the consent of our husbands because it is only our husbands who have access to our private parts. So if you also want to do something there, you have to seek the consent of our husbands and that is a challenge."* (WWHNS 5, 36 years).

Another respondent also explained:

> *"Some want to discuss with their husbands and seek their husband's consent and all that. Some too are not just comfortable with the procedure."* (WWHNS 6, 24 years).

As the heads of families, men in the Battor community play a critical role in women's decision to seek treatment. One cervical cancer patient reported that she delayed seeking treatment on the advice of her husband. She said:

> *"When I complained to my husband about what was happening to me, he suggested that I observe it a bit longer but I realised nothing changed"* (CCP 1, 34 years).

Belief in Traditional Medicine

Another socio-cultural factor identified from this study as barrier to screening of the disease was the belief in traditional medication. Even though some acknowledged the importance of going to the hospital, they believe traditional medication had to be sought first. As a result, they rather used local herbs first before going to the hospital. The use of local herbs or medicine stemmed from the belief that traditional health care is an important alternative source for seeking health. A male respondent said:

> *"In the past, we did not go to hospital; we took leaves and we were strong. That is the natural order"* (MFGD. 2).

Another said:

> *"Some people also say that some herbal medicines do cure all diseases. So instead of going to screen why not take herbal medicine to even prevent it."* (MFGD 2).

The danger of resorting to such traditional interventions is that it mars one's opportunity to receive a comprehensive and appropriate treatment plan for the disease.

Institutional Level Barriers to Seeking Cervical Cancer Screening and Treatment

Institutional level barriers were considered in relation to the behaviour of the health personnel during the process of screening and treatment. Three (3) barriers were reported by respondents in relation to the health worker: attitude, privacy and confidentiality. Respondents who had never been screened also raised concerns about the attitude of some health personnel. Some respondents mentioned that they had experienced unfriendly attitudes of some of the health workers from previous visits to health centres. These included lack of sympathy and empathy, neglect, shouting at patients, frowning at patients, being treated harshly, health workers not wanting to touch patients, judgemental behaviour and not listening to complaints. They indicated that such unfriendly attitudes of the health personnel are a sign of disrespect and as such they did not want to experience such disrespect from persons they are older than. The following statements were made by some of the respondents:

> *"If the people examining me are not friendly, or if they do not explain things better to me, I might withdraw from doing it."*(WWHNS 4, 37 years).
>
> *"If the health providers are not friendly...I am not sure I will go for screening".* (WWHNS 10, 31 years).

Some of the cervical cancer patients also expressed their frustrations towards the health personnel.

> *"They treated me badly when I went to other hospitals"* (CCP 5, 44 years).
>
> *"I went to various hospitals but I was told I had no problem".* (CCP 2, 43 years).

These statements were consistent with the observations made during the fieldwork where some nurses treated the patients badly. There were times when some nurses simply ignored patients who were talking to them. On other occasions, some nurses were heard shouting at the patients.

The respondents explained that because of the unfriendly attitudes of health workers, they do not believe the health personnel would respect their privacy and keep their results with confidentiality. The respondents felt that their privacy would be invaded because health workers will disrespect their bodies. One of them said:

> *"It will take a huge effort for me to open up my private part to another person. And even when I have made such an attempt, these people might touch it anyhow with their left hand."* (WWHNS 3, 43 years).

The environment in which the nurses and doctors did the consultation was too open. Observations during the study revealed that confidentiality was somewhat breached, given the nature of the consulting room setting. Ideally, each doctor should have a consulting room of his or her own where privacy could be safeguarded; but the reality was that two doctors shared a consulting room. Due to the sitting arrangements of the consulting room, a patient narrating her story could be heard by another patient. Patients could be seen being hesitant in narrating their conditions. Also, patients were observed to be waiting for long hours to see the doctor, with some spending as many as eight (8) hours, and this could negatively affect the willingness of other women to undergo screening.

Policy Level Barriers to Seeking Cervical Cancer Screening

Respondents raised a number of concerns that are related to the absence of a comprehensive health policy on cervical cancer. Some of the respondents reported that they would have gone for screening if adequate education or information had been given to them through the media. These were the statements made by some of the respondents:

> *"Well, I do not think awareness had been created enough about the disease and that is the problem. Women would not come voluntarily to tell you they have heard of any screening and they want to do it. They should educate us enough through the media and other ways of education and then we can go for it*". (WWHNS 4, 37 years).

> *"Education about cervical cancer in the media is not that high. All we hear is about breast cancer and other cancers but cervical cancer per se is not adequate on television and radio. Unless the government makes provision for adequate education about the disease and how important it is to all our females, they will not come out to do the test. I personally believe that the more they talk about it, the more other people who did not have any idea about the condition will come out and say they want to perform the test*". (WWHNS 10, 31 years).

Respondents complained of high cost of screening in the absence of government subsidy for cervical cancer screening services. Some respondents reported that even though they were aware of the disease, they could not afford the prices being charged for the screening. They further explained that government did not subsidise the cost of screening to make it cheaper and affordable. Some suggested the services should be free for every woman in the communities to access. This, according to the respondents, had constrained their ability to go for screening. A respondent had this to say:

> *"I think much attention is not given to the disease. Everybody can afford it and maybe even go a step further to get screened, if it is cost effective for us"*. (WWHNS 3, 36 years).

Another respondent also said:

> *"Some of us cannot pay for the cost. Because they asked us to pay, they end up getting few people taking part. Not everyone can get money to do the test. But if the screening and some of the treatments are for free, a lot of people will get involved. And if the victim is put on treatment and recovers, she can become useful to the state. Therefore, government should regularly help everyone for them to take part in the screening*". (WWHNS 7, 37 years).

For those living at the periphery of Battor, availability and accessibility to screening and treatment facilities was another policy issue that emerged. Most respondents identified this as a factor militating against the uptake of screening and treatment for the disease. Some of the respondents reported that there was no screening and treatment facility in their neighbourhood, since they were coming from quite a remote area. This made it difficult for them to come for screening and treatment. Some respondents therefore admitted that if more screening and treatment facilities could be built close to where they come from, it may well help in improving uptake of screening and treatment. Some of the respondents made the following statements:

> *"Some of us are coming from a rural area where there are no health facilities. We have to come this far before we can*

> *come and screen. If only government can provide more health facilities, it will promote the uptake of cervical cancer screening and treatment in our communities".* (WWHNS 9, 46 years).

> *"Some of the women come from remote villages where there are no health facilities. Considering transportation challenges, it becomes difficult for these women to take part in the screening. If more hospitals where the tests can be run are made available in these communities, more women would get involved and would not have travelled all the way to this place just to do the test".* (FFGD 1).

Perspective of the Health Personnel

The health personnel corroborated virtually all the issues raised by the respondents during the interviews. Some health personnel also reported the low level of knowledge about the disease as a barrier to the uptake of screening. According to the health personnel, the women did not know much about the disease so they start treating it with their own herbal medication before coming to the hospital when the condition gets worse. The following was a statement made by the health person:

> *Some of the women use herbal preparations. Some actually do not know what is wrong with them. They start treatment on their own, inserting all kinds of herbs and things but when it is not working and the condition deteriorates, then they come to*

> *us. But I think they do not have adequate knowledge about the condition"*. (HP 2, 36 years).

Some of the health workers interviewed also raised the issue of low level of income among the rural women as one of the factors for not accessing screening. The health workers reported that they had been living in the community with the women for some time now and they believe the inability of the women to come for screening was because of their low income level. The following were the statements of some of the health personnel on the issue:

> *"Looking at the terrain here (I am not talking of those who come from other parts of the country who come to the clinic. I'm referring to those from the remote part of the district), some of the women earn less than 10 Ghana cedis a day. I know this because I am in the community. So I know that even 10 Ghana cedis is difficult for them. So I am advocating that with the new screening that we are going to do for free, we go to where they cannot afford"*. (HP 3, 47 years).
>
> *"Some of the women come here without enough money, especially those from the rural areas. They do not have enough money but we do our best to actually see to them. We do not neglect them; we just tell them to go and search for some funds. Sometimes, when the family members get involved, we convince them to assist the patients"*. (HP 4, 36 years).

In an in-depth interview with one of the health personnel, she tried to compare the prices charged by other facilities in the country with what they charge. She reported that by far, the Battor Catholic Hospital was the health facility that offers screening services at the lowest price in Ghana. Yet, the women in the rural communities in the catchment area of the facility could still not afford the screening service. The following was her statement:

> "*35 Gh cedis for a Pap smear is the cheapest in Ghana. But even that is expensive for the women here. So it is difficult to get them to screen. Some of them cannot still afford*" (HP 5, 27 years).

The search for divine solutions also emerged as a barrier to treatment itself. In-depth interviews with health workers revealed that women with cervical cancer sometimes seek spiritual remedies instead of coming to the hospital for treatment. Some health workers attributed this to regular testimonies in the mass media by people who claim to have received spiritual healing in order to promote these spiritual healers and increase their clientele. Default in seeking treatment at biomedical facilities occurs in favour of spiritual healers. The following were the statements made by some health personnel:

> "*...When you give them referral letters to go to other hospitals for treatment, some [people] do not go. They end up in prayer camps. I was called once, there was a prayer camp that a woman who had come to this hospital and was diagnosed with cervical cancer had gone to and as soon as they prayed for her; they claimed the cervical cancer was gone [healed]. I wonder how she got to know that the cervical cancer was gone*". (HP 2, 36 years).

"The problem with patients defaulting in treatment comes from deceits, usually from religious leaders who claim to have all forms of treatment in prayer camps. Some [cervical cancer patients] go and when they eventually do not get well, then they come back sometimes bleeding more". (HP 5, 27 years).

From the health personnel's perspective, the engagement of women in these herbal interventions, which do not have the efficacy to heal the condition also poses as a barrier to the screening and treatment of the condition. The health personnel hinted that women's belief in herbal medicines to alleviate the disease hinders appropriate action to proper health seeking behaviour. This is reflected in the following statements made by some health personnel:

"Ooh!! They go to the herbalists. There is a herbalist in town. They say it is a clinic and I think he is deceiving them. The women with cervical cancer are patronising there even more than this hospital now. They go there and when it gets worse, then they run to the hospital and sometimes, they come too late". (HP 3, 47 years).

"It is because of the herbal treatment. These days, we see every van carrying herbal preparations with different names. One medicine they will say cures all kinds of diseases. Some insert herbs, some drinking it, some washing their vagina with all kinds of medicines. They do all those things and if there is no improvement before they come and for some, they come at the advanced stage." (HP 5, 27 years).

The health personnel believed that, women are obliged to ask for consent from their spouses before seeking healthcare. They explained that, this is due to the prevailing normative gender relations in the setting. As a result, a number of men feel uncomfortable allowing the wives to come for screening, since it has to do with their private part. This is reflected in the following statements:

> *"Some want to discuss with their husbands and seek their husband's consent and all that. Some too are not just comfortable with the procedure"*. (HP 1, 24 years).
>
> *"For some of the people who are in very remote areas, they have to seek the consent of their husbands because it is only their husbands who have access to their private parts. So if you also want to do something there, they have to seek the consent of their husbands and that is a challenge"*. (HP 2, 36 years).

Acknowledging the male as the head of the household was also an issue. The gender roles place greater responsibility on men to meet the health needs of the women and make decisions for them. This notion was not only held by women from the community, they were also affirmed by the health personnel who dealt directly with indigenes of the community. This is what a health personnel had to say:

> *"Like any rural community, men have so much power and in some of the communities, the woman cannot even come to the hospital without asking the man for money to come. And we see it here especially in the poor villages. So if men who are not actively involved are not made to understand the benefits of screening, it will be difficult to get the women to screen*

because the men have so much power in deciding on what the woman should do, including coming to the hospital". (HP 4, 36 years).

Discussion

This chapter examined the barriers to cervical cancer screening. Data from in-depth interviews with ten women and five focus group discussions were used. Barriers to the uptake of cervical cancer screening were considered at the individual, community, institutional and policy levels. The discussion is organised according to these sections.

At the individual level, the uptake of cervical cancer screening among the women was constrained by low level of knowledge of the disease, psychological and economic factors. Most of the women indicated a lack of knowledge about cervical cancer, and screening opportunities. This is consistent with other studies which have concluded that in the low and middle income countries including Ghana, knowledge and awareness of cervical cancer and screening is very low (Fort et al., 2011; Paolino & Arrossi, 2011; Duran, 2011; Ansink et al., 2008; Williams and Amoateng, 2012).

The relationship between the low level of awareness about cervical cancer and seeking of screening can be explained by concepts from the Health Belief Model. As suggested by HBM, the lack of knowledge about a disease reduces perceived susceptibility (Glanz et al., 2008; Ben-Natan & Adir, 2009). Therefore, for individuals who believe they are not at risk, the perceived benefits of seeking cervical cancer screening are irrelevant. In addition, the lack of knowledge about the disease reduces self-efficacy. In other words, the low level of knowledge reduces self-competence to overcome the potential barriers to seeking screening services (Russell et al., 2006).

The fear of screening itself, screening outcomes, diagnostic procedures and treatment also played a major role in making women refrain from cervical cancer screening (Agurto et al., 2004; Basu et al., 2006; Parsa, Kandiah, Rahman, & Zulkefli, 2006). From their experiences, some women feared misdiagnosis of the disease and these factors prevented screening for the disease (Marlow, Wardle, & Waller, 2015).

Evidence from several studies has indicated that economic factors, particularly low income or high cost of screening, were a major barrier to screening and early diagnosis of the disease. For instance, Basu et al. (2006), Keshavarz et al. (2011), Williams and Amoateng (2012) indicate the importance of socio-economic constraints as a barrier to early screening and treatment of the disease. Poverty was cited by some of the respondents as the reason why women could not go for screening services. This can be deduced from how some were unwilling to pay small amounts for screening. This may be as a result of the fact that the respondents were mainly housewives who were not earning any income; and even those who were employed were only engaged in petty trading and therefore earning very little and could not afford the cost of screening and treatment charged by the health facilities.

Other studies, however, have revealed that merely having a higher income does not guarantee the uptake of cervical cancer screening. Instead, it may involve other factors such as knowledge and perceived seriousness of the disease (Wellensiek et al., 2002). This can constrain screening and treatment by either delaying the uptake or preventing entirely. However, there are free screening services offered in some public hospitals in Ghana. Therefore, education on such opportunities are recommended (Williams & Amoateng, 2012).

At the community level, gender norms and belief in traditional medicine were identified barriers to cervical cancer screening. Women, particularly the older ones, felt shy and embarrassed at exposing their nakedness to health personnel, especially males, when they go for screening. This has consistently emerged in a number of studies (Keshavarz et al., 2011; Parsa et al., 2006; Ansink et al., 2008).

The belief that cervical cancer was caused by retribution from God or the gods for wrongdoing or that the disease was as a result of a curse for sexual promiscuity constrained their propensity to go for screening. Being diagnosed of cervical cancer meant that the person was unfaithful as well as immoral (Fernandez et al., 2009). Some women sought alternative solutions including divine interventions at churches and traditionalists as well as resorting to traditional medications that delayed or constrained going for screening for the disease.

Gender relations also emerged as barriers to screening and treatment. Some of the women reported that they needed to seek approval from their partners, either verbal or financial, before they could go for screening for any particular disease. Thus, some of the married respondents could not take the initiative when it came to issues concerning their health. For some women, it was difficult for them to convince their partners to provide emotional or financial support to visit a healthcare facility for screening, especially if they are not visibly ill (Keshavarz et al., 2011; Fort et al., 2011; Bingham et al., 2003). Therefore, their attendance of screening may likely depend on the male partners' approval and willingness to support the women emotionally.

At the institutional level, attitude of health personnel and the issue of confidentiality with medical information were revealed as one of the factors militating against screening for the disease. This is consistent with the results of a number of studies from Botswana (McFarland, 2003). For example, McFarland (2003), Agurto et al. (2004) and Mutyaba et al. (2006) note that the inability to maintain confidentiality of test results, rude behaviour of some health personnel as well as concerns about privacy during screening served as barriers to the uptake of screening services.

The women perceived the attitude of the health personnel in terms of friendliness as well as the ability to keep medical information confidential as a crucial factor in going for cervical cancer screening. Poor interpersonal relationships create a communication barrier that prevents health workers from giving women the information they need about cervical cancer, screening, symptoms, causes, prevention and treatment. Hence, perception about the attitude of the health personnel could be important in improving uptake of cervical screening. Gynaecological health workers are often overworked and with great responsibilities to provide services to all women seeking gynaecological help. Therefore, support can be offered to health workers through training in communication and counselling skills (Adanu et al., 2010).

Inadequate education about the disease served as a policy level barrier to screening. The respondents explained that there was no adequate education or sensitisation about the disease in the media. Studies have indicated that improving education on cervical cancer screening increased knowledge on cervical cancer and screening uptake (Daley et al., 2011; Nguyen et al., 2002; Tung et al., 2008). For some, the cost of screening was a challenge to screening uptake (Daley et al., 2011). Respondents were of the view that the cost of screening and treatment should be subsidised or made free and services provided in rural communities to motivate them to go for screening and treatment.

Conclusion

This chapter examined the barriers to cervical cancer screening among women. The findings indicated that: (1) individual (low level of awareness about cervical cancer; psychological and economic factors); (2) community (gendered norms and belief in traditional medicine); (3) institutional (health worker attitudes; and (4) health policy factors, inhibited women from seeking screening services. This study therefore recommends a comprehensive cervical cancer prevention and treatment strategy that includes education, subsidy and health worker education. Interventions to improve knowledge and understanding of the benefits of seeking cervical cancer screening could be beneficial to the community. These interventions could address the causes, symptoms, availability of free screening services and issues related to stigma and cultural beliefs associated with cervical cancer.

CHAPTER EIGHT

KNOWLEDGE AND ROLE OF MALE PARTNERS IN SCREENING AND TREATMENT

Introduction

Promoting male involvement in the health of their partners, as in other areas of social development, can be an advantage in the treatment of cancer. The importance of involving males in cervical cancer screening and treatment decisions becomes necessary because it is a means by which men relate to reproductive health problems, programmes, rights and the behaviour of women.

This chapter relates to study objective four that seeks to explore the knowledge of partners of cervical cancer patients about cervical cancer as well as the roles played by the male partners in the screening and treatment of their female partners from the perspective of both the male partners and the patients. The willingness of males to support their wives if they were diagnosed with the disease is also presented in this chapter. The Socio-ecological Model informed the interpretation of the findings.

Background Characteristics of Male Partners

Six partners of cervical cancer patients participated in the study and their background characteristics have therefore been summarised. Four of them were between 50 and 59 years, while one was aged 40 and another 49. Three out of the six had tertiary education while two had secondary school education; only one had primary education. Four out of the six were self-employed while one was a government employee whilst another was employed in the private sector. Five of the respondents had between four to six children while only one had between one and three children. They were all Christians and none of them was a smoker. Four of them were reported to be currently drinking alcohol while two were not drinking alcohol.

Knowledge of Cervical Cancer

In the interviews, partners of the patients with cervical cancer were asked about their knowledge of the disease before their partners were diagnosed of the disease. The male partners reported that they had no knowledge concerning the causes, symptoms and risk factors of the disease prior to the diagnosis of their partners. Some also explained that they did not even have a local name for cervical cancer. All the six partners of the cervical cancer patients said they never knew anything about the disease prior to the diagnosis of their wives. One of them said:

> *"I did not know about anything like that. I did not have any idea about the disease. I only overheard it on the television been debated in Parliament as to whether it should be covered in the national health insurance scheme. That is all"*. (PCCP 3, 50 years).

Another said:

> *"In fact, I have no knowledge about the disease and how it started or came about, but all I knew was that it could kill. And I do not even know its local name"*. (PCCP 6, 58 years).

Those who got to know about the disease after the diagnosis of their partners explained that they still could not tell causes, symptoms and risk factors of the disease. The doctors only provided them with general knowledge about the disease. This can be inferred from the following statements made by two of the male partners:

> *"I do not know about its transmission; but I know that it is not infectious and there is a possibility of the cancer spreading to other parts of the body. This, I was told by the doctor. But transmitting it to other people, I have no idea".* (PCCP 2, 58 years).
>
> *"Well, about that condition, the doctor explained it to us but I have forgotten exactly what it is. But, I know it had to do with only women. Just like we men have the prostate cancer".* (PCCP 4, 51 years).

The male focus group discussants also had misconceptions about the disease as illustrated in the two statements below:

> *"Some men have long organs that scratch women's wombs during sex. You know when it scratches the womb it causes injury over time leading to cancer"* (MFGD 2).
>
> *""Some women take in herbal medicines to abort babies. When that happens, sores develop around their genitals leading to the disease"* (MFGD 2).

Role of Male Partners in Cervical Cancer Screening and Treatment

In this study, most of the cervical cancer patients reported that their partners provided them with various forms of support during the screening and treatment stages of the disease. These included financial, social, non-material as well as emotional support (Table 11).

The male partners explained that they supported their wives financially, socially, emotionally and non-materially during the screening and treatment of the disease. In this regard, one male partner reported that whenever his wife was going for treatment, he gave her money for transportation and payment of bills, even though his company eventually paid the bills. Another male partner also reported always taking care of the house financially and assisting the patient by working in the shop she owned.

Table 11: Support Provided by Male Partners in Screening and Treatment

Category of support	Specific supports
Financial	Screening and treatment expenses, transportation
Social	Accompanying her on her hospital visits, prayers, visits,
Non-material	Cooking, washing, taking care of home, assisting in working the shop she owned
Emotional	Sexual abstinence, encouragement

Source: Fieldwork 2014

The following were the responses of two male partners:

> *"I gave her all the necessary things that she needed. Sometimes, I borrowed money; sometimes too, I had to sell my things. Luckily enough, her company also came in and helped her a lot. But it is been five months now without working and as the head of her department, someone had to replace her".* (PCCP 3, 50 years).
>
> *"I assisted her financially and when it came to cooking, I gave money to the kids to take care of that. Also, I had to take a casual leave to assist her and accompany her to the hospital".* (PCCP 6, 58 years).

Another role some male partners played in supporting their female partners during the treatment phase was to abstain from all forms of sexual relations with the patients. A partner recounted feeling so frustrated by the condition that he had to go and seek sexual satisfaction outside the marriage. Some partners of the patients also reported that they found it difficult having sex with their partners after the diagnosis because of the pain and bleeding associated with the disease.

They further explained that they knew that their partners could suffer post-coital bleeding even after they had commenced treatment. As a result, they tried to completely abstain from sexual intercourse with their partners in order to support the recovery process of their partners. Some also indicated that they had diminished appetite for sex with their partners because of the nature of the condition.

One of the partners made the following statement:

> *"After my wife's treatment, I became scared to get involved with her sexually. But we are okay with that. But when I told her that I was scared to have sex with her, she thought about it for some time and felt sad and she even cried".* (PCCP 3, 50 years).

Another two male partners also indicated that:

> *"I will say that sex is completely out of my life".* (PCCP 5, 63 years).
>
> *"It had affected me a lot, since anytime I wanted to have sexual intercourse with my wife, her bleeding comes to my mind. I was therefore scared for her. So I sometimes had to go out and have sex with my girlfriend".* (PCCP 6, 58 years).

However, not all male partners supported their partners through the screening and treatment process. Three cervical cancer patients recounted that they had no support of any kind from their male partners. One of the cervical cancer patients shared her experience:

> *"I remember there was a time I even needed just 300 Ghana Cedis and nobody helped me. Even the church I was then attending, they disappointed me".* (CCP 1, 34 years).

Two others also shared their stories:

> *"Because of the disease my husband left me and went to marry another woman. So we are no more together. Only my child is helping me*". (CCP 4, 44 years).

> *"I have no support; I do everything on my own even though I was advised by a nurse not to lift heavy things after I was discharged from the hospital. I was told by other nurses that if I continue to lift heavy things, the stitches may tear"*. (CCP 6, 63 years).

Willingness of Other Men to Support their Partners in Screening and Treatment of Cervical Cancer

Men from the Battor community who took part in the FGDs expressed their willingness to support cervical cancer screening and treatment. The men said they would encourage their partners to go for screening and would also not hesitate to take them to the hospital for treatment. They however felt handicapped by their lack of knowledge of the disease. As a result, some indicated their willingness to discuss the condition with the health workers to have a better understanding of the disease and help to find solution to it. This is indicated in the responses below:

> *"Women do not understand why they should even go for the screening even when they say it is free. I think that will encourage them to go for the screening if that will prevent them from getting the disease"*. (MFGD 5)
>
> *"Because of poverty women wouldn't like to go for screening. I will encourage them to go for the screening it is dangerous disease*". (MFGD 2).

According to the men, they will provide any form of support including financial support for their wives to be treated. The following were the responses of some of the respondents during the focus group discussion:

> "*I will seek medical treatment from hospital; that is what I will do. I will take her to the hospital for the treatment*". (MFGD 1).
>
> "*I have to rush to the hospital with money. Quickly approach the medical officers to find solution to cure the cancer*". (MFGD 2).
>
> "*If I am told that my wife has cervical cancer, definitely, the doctor will give her advice. So when she told me what the doctor told her, I will support her based on what the doctor told her and then I will send her to do whatever they told her to do*". (MFGD 2).

From their responses, the men seemed to recognise the serious nature of the disease and were willing to offer any kind of support, be it financial, social, emotional or non-material, if their female partners were diagnosed with the disease. They appreciated the need for screening as a preventive measure and were therefore ready to encourage their partners to go for screening.

Discussion

This chapter is centred on assessing the support given to cervical cancer patients by their male partners during the screening and treatment process. This was looked at from the perspective of both the patients and their male partners. The chapter also tried to assess the level of knowledge of male partners about the disease. The interviews showed that like the women, the male partners had little or no knowledge about the cervical cancer disease. It has been observed that the male partners did not have any information about the causes and symptoms of the disease as well as the risk factors of the disease. Even the few male partners who had a little knowledge about the disease had it from the doctors or health personnel after the diagnosis of their female partners.

Respondents revealed that the information given them by the doctors was generally about the nature of the disease and not about the specific causes, symptoms and risk factors. Hence, the respondents had no previous knowledge of the disease. This is consistent with findings of Maree et al. (2011) as well as Williams and Amoateng (2012), that men have inaccurate or no knowledge of the cervical cancer disease. The implication of this situation is that men will hardly identify what exactly is wrong with their wives or female partners in order to take the necessary steps quickly enough to help save the lives of their female partners. This may prompt the need to also involve men in any cervical cancer education or programmes.

From the interviews conducted, it came out that male partners had supported their female partners in diverse forms during the screening and treatment processes of the disease. Male partners were reported to have played the role of financiers during the screening and treatment of the disease. Both the female and male partners confirmed that the male partners provided a number of supports during the screening and treatment process. The issues of social and emotional support from the male partners were also highlighted in the study results. Male partners supported their female partners as caregivers during the critical stages of the disease by sharing the pain of their partners and accompanying them to the hospitals or clinics whenever necessary.

Only a few male partners of the cervical cancer patients were reported to have abandoned their partners without any form of support during the screening and treatment period of the disease, forcing some patients to manage without support in virtually everything. Regardless of this, other studies, Thiel de Bocanegra et al. (2009) and Williams and Amoateng (2012), have established that male partners play a critical role in supporting their female partners in cancer screening and treatment activities. It is important to recognise the significant role of men in the health behaviours of some Ghanaian women (Williams & Amoateng 2012). Including males in cervical cancer education programmes, therefore, may be a crucial component in cervical cancer screening and treatment (Trevino et al., 2012).

In this study, attention was drawn to the peculiar nature of the disease as a genital cancer that demand the support and understanding of partners of sufferers. The study showed that, as a form of support, partners of cervical cancer patients had to accept to abstain from sexual activities. The men explained that abstaining from sex with their partners would reduce the pain and bleeding and also prevent any interruption in the treatment regimen and hasten the healing process. Sexual abstinence with the patient will also help to quell the heavy blood flow and pains associated with the disease. Without an understanding of the situation, male partners may not be willing to sacrifice their sexual pleasure. This could lead to possible divorce or neglect of the cervical cancer patients. The male partners could also use the situation as an excuse to indulge in adultery.

Men from the Battor community, whose partners were not suffering from cervical cancer, were also keen on offering any form of support to their wives if they ever contract the disease. In addition, they were also willing to encourage their partners to go for screening. Similar findings were also observed by Williams and Amoateng (2012). The men believed that they will quickly seek medical attention for the disease and provide any necessary support that will be prescribed by the medical personnel, in order to help treat their wives.

Conclusion

This chapter examined the knowledge and role of men in cervical cancer screening and treatment. Even though the male partners were not suffering from had little or no knowledge of cervical cancer, most of them supported their wives financially, socially, emotionally and non-materially. Men whose partners were not suffering from cervical cancer patients were prepared to provide financial, social, emotional and non-material support to their partners if they were ever diagnosed with the disease. They expressed the wish to encourage their partners to go for early screening.

From the results, it appears that men can play a critical role in removing some of the barriers to cervical cancer screening and treatment. It is therefore important for men to be also targeted in campaigns for them to encourage women to go for screening and also provide support for the treatment when diagnosed.

CHAPTER NINE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

This chapter presents a summary of the results, draws conclusions based on the findings and provides the relevance of the theoretical issues. The last section of the chapter discusses the policy implications of the findings as well as areas for further studies.

Summary of Main Findings

The main objective of the study was to assess barriers to screening and treatment of cervical cancer among women in a rural setting in Ghana. The specific objectives were to: (1) assess the knowledge, perception and experiences of women living with cervical cancer; (2) explore coping strategies and health seeking behaviour adopted by cervical cancer patients to manage the disease; (3) determine the factors that constrain cervical cancer screening; and (4) examine the knowledge and role of male partners in cervical cancer screening and treatment.

Knowledge, Perception and Experiences of Women Living with Cervical Cancer

Results from the study revealed that majority of the cervical cancer patients had no knowledge about the disease prior to contracting and diagnosis of the disease. As a result, the initial symptoms of the disease were misinterpreted as natural changes due to changes in the menstrual cycle, aging and menopause. The patients became aware of what was happening to them only after they had undergone screening. The patients were also not aware of the causes, symptoms and preventive behaviours as well as the risk factors of the disease and the population at risk. A number of the patients did not think that they were susceptible to the disease because they were married or were too old to suffer from such ailments.

Cervical cancer was found to be disruptive to the wellbeing of the women. The women experienced physical, psychological, social and economic disruptions. These disruptions brought changes to their socio-economic lives. For example, some of the women run into debts due to the high cost of treatment and other personal expenses associated with managing the disease. Some of them lost self-confidence due to their condition while others were rejected by their relatives including the partners.

Coping Strategies and Health Seeking Behaviour of Patients

The women adopted personal, psychological and social support networks to resolve the challenges associated with cervical cancer. At the personal level, the women abstained from sex during the period of treatment. To be able to live a normal life, patients had to use hygienic materials including sanitary pads, cloth and towels to contain the heavy flow of blood and disinfectants to prevent the strong vaginal odour associated with the disease.

The women also adopted psychological coping mechanisms such as ignoring the condition or pretending it did not exist. Another psychological coping mechanism used by some women was belief in God. The respondents explained that in times of emotional or physical difficulties, they had to go to church to pray to God for mercy and healing. Some patients even reported having to travel long distances to consult religious leaders for healing.

Other sources of support were from their partners, children, other family members as well as religious organisations and associations. The support from these sources included financial, emotional, non-material and spiritual support. They explained that the support from various categories of people and organisations helped them to cope effectively with the condition.

Some male partners provided emotional, social and financial support to their spouses during the screening and treatment periods of the disease. Most male partners paid for screening and treatment and escorted their spouses to health facilities for treatment. Other family members who provided support included siblings, nephews and nieces.

The women used a combination of faith healing, orthodox medicine and herbal medicine. Some respondents started with prayers and then to orthodox medicine. Some women felt that the biomedical approach alone was not helping them and therefore had to resort to herbal medication. Some also experienced complications arising from the use of herbal medicine and had to resort to biomedical and faith healing.

Barriers to Cervical Cancer Screening and Treatment

The study found a number of barriers to cervical cancer screening and treatment at the individual, institutional, community and policy levels. At the individual level, it was observed that low level of awareness of screening and treatment of the disease was a barrier to screening and treatment. Most women did not have any knowledge of the disease and were unaware of available screening and treatment opportunities. Hence, there was low uptake of screening and treatment of the disease.

Psychological barriers observed included fear of diagnosis and perceived fear of death after diagnosis. Furthermore, shyness and embarrassment felt by most women during screening and treatment emerged as barriers. Most women felt shy and embarrassed to expose their nakedness to health personnel, particularly the male. The issue of pain and anxieties associated with the screening procedure were other inhibiting factors. Women perceived that the insertion of metals and some other gadgets into their vagina would cause them pain. Economic barriers that emerged included the cost of screening and treatment of the disease. The women felt the cost of screening for cervical cancer and treatment was too high and unaffordable and for that reason they did not avail themselves of the screening and treatment services available at the hospital.

At the institutional level, the attitude of health personnel and issues concerning confidentiality were the barriers identified by respondents. Respondents cited unfriendliness and lack of trust in handling confidential health information on the part of the health personnel as some of the factors that constrained their uptake of screening and treatment of the disease.

Observing the processes cervical cancer patients went through at the health facility, it was noted that some of the nurses were particularly hostile to the patients. Space provided for consultation was rather too small, denying the patients the privacy they needed to talk to the doctor about their condition. In addition, patients had to wait for long hours to see a doctor, with some spending as long as eight hours. In spite of these conditions, some patients appeared willing to endure the situation without complaining. There was also the issue of previous misdiagnosis at the health facilities, which prevented some women from going for screening later on.

At the community level, the socio-cultural factors had to do with the belief system of the communities. For instance, there was the belief that cervical cancer was caused by promiscuous lifestyles or was a punishment from God. There was also the view that it was an abomination for other people, apart from the husband, to see the nakedness of a married woman. The women were therefore not willing to go for screening for fear of being attended to by a male doctor. There was also a general belief in traditional medicine. Some patients resorted to divine interventions through churches and traditional healers instead of visiting health facilities for screening and treatment of the disease.

Normative gender relations served as one of the socio-cultural barriers to the uptake of screening and treatment of the disease. In some instances, women needed the approval of their husbands in order to go for screening and treatment. They also depended on their husbands or men for financial or social support before they could go for screening and treatment.

At the policy level, one of the barriers that emerged was low level of education or sensitisation on the disease. Respondents explained that they were not aware of the disease in their communities. There was also the inability of government to subsidise cost of screening and treatment services to make the services affordable to rural women.

Availability or accessibility to screening and treatment facilities was another barrier that emerged. Some respondents reported that they had to travel over long distances for screening and treatment.

Knowledge and Role of Male Partners in Cervical Cancer Screening and Treatment

Partners of cervical cancer patients had little or no knowledge of cervical cancer. The male partners lacked knowledge of the causes, symptoms and risk factors of the disease. The few who had a little knowledge of the disease had it from health personnel after the diagnosis of their female partners. Male partners had provided a number of supports to their women in diverse forms during the screening and treatment processes of the disease. These included financial, social, emotional and non-material supports. Male partners of non-patients who participated in the focus group discussions were also keen on providing financial, social, emotional and non-material support for their female partners if they were diagnosed with the disease.

Conclusions

The study examined the challenges associated with cervical cancer screening and treatment in Battor in the Volta Region of Ghana. In-depth interviews were conducted with fifteen cervical cancer patients, six partners of cervical cancer patients, ten women who had never been screened for cervical cancer and focus group discussions were conducted for men and women in the Battor community.

Generally, the use of a combination of research instruments helped to enrich the study data. In-depth interviews, focus group discussion (FGD) and observation tools made it possible to capture the various dimensions to low uptake of cervical cancer screening and treatment in the study area. Also, the inclusion of varied respondents such as women who had never been screened for cervical cancer and men from the Battor Community helped to deepen the understanding of barriers to cervical cancer screening and treatment. It also gave insights into how members of rural communities perceived diseases that affect women, their causes, symptoms, prevention and treatment.

The lack of adequate knowledge on cervical cancer among both cervical cancer patients and those who have never been screened point to the need for an intensive health education. This has been exacerbated by lack of funding or subsidy and unavailability of health facilities. Cervical cancer was disruptive to the social, economic and psychological health of the respondents. Cervical cancer patients adopted personal, psychological and social strategies to cope with the disease.

The policy level barriers had to do with low education about the disease, lack of funding or subsidy and unavailability of health facilities. While partners played an important role in supporting patients during the screening and treatment process, they were unaware of the situation of their partners and females generally. Men whose partners did not have the disease were willing to support their wives if they got infected, provides a potential avenue for engaging men in education on the disease.

The Concept of Biographical Disruption in particular was helpful in understanding the lived experiences of women with cervical cancer. There is very limited information on how their condition affects them, their relatives and communities as a whole. The study provided knowledge on how the disease disrupts the body, social identity, livelihood, family and social relationships. The paradigm was useful in identifying the wider context of the implications of a disease on the lives of infected persons and other members around them.

Studies conducted on cervical cancer in Ghana over the past decade have been rather clinical in nature and devoid of the psychosocial aspects of the disease (Adanu, 2002; Awua, Sackey, Osei, Asmah, & Wiredu, 2016). This study has provided the psychosocial perspective on screening and treatment of the cervical cancer disease and coping strategies of infected persons. Although the disease is associated with the female genital and also stigmatised, its implications have not been given as much attention as other diseases such as HIV. The results of the study provide pointers to the need to give attention to NCDs since Ghana is experiencing the double burden of diseases (Ghana Health Service, 2014).

There is lack of literature on the coping strategies or mechanisms for managing the cervical cancer disease condition. Consequently, this study provides literature to fill the gap on coping strategies as well as men's involvement in screening and treatment of the disease.

The study is also unique because it is one of a few qualitative research work that included both cervical cancer patients and their partners in the same study and obtained their lived experiences with the disease as those infected and affected. It further obtained data from different categories of people such as men, women and health personnel to obtain varied opinions to achieve the objectives of the study.

Policy Implications of the Study Findings

The findings indicated lack of knowledge about cervical cancer among patients and individuals who had not gone for screening. Efforts should be made to provide sustained and improved health education for women on cervical cancer. Cervical cancer education programme should be incorporated into the Regenerative Health education programme. In addition, cervical cancer education should be integrated into CHPS Compound system with community nurses equipped to organize health education talks on cervical cancer in the communities.

There should be concerted efforts by health professionals, the government, Non-Governmental Organisations and the media to intensify health education on cervical cancer screening and treatment. Efforts towards prevention and management of cervical cancer should include sustained awareness creation and improvement in service delivery. Creating awareness should go hand in hand with the necessary support systems. For instance, the system should work towards free screening services at public health facilities.

Furthermore, screening and treatment facilities are needed to aim at promoting the health of all women. To do this, a dual approach may be necessary: (1) it can be community-based through the CHPS system and (2) health facility-based to provide point of care test, see and treat care, as well as care for women who are likely to be lost to follow up. There would also be the need for multiple screening methods among women including Visual Inspection with Acetic acid (VIA), Cytology (Pap smear) and HPV testing. Health personnel may also need further training and skills building in accurate diagnosis of the disease, good client relations as well as the issues of privacy and confidentiality.

Counselling, although found to exist, did not seem to meet the needs of patients and their relations. Therefore, functional counselling units should be established for patients and relations and should incorporate the different levels of disruption that women experience as a result of the disease and how the situation could be managed. Lessons could be learnt from good practices in HIV counselling that have been carried out over the years (Conkling et al., 2010).

Financial constraints served as barriers to the uptake of screening and treatment of the disease. Most of the women in the study faced financial challenges and therefore found the cost of screening and treatment too high. Through the health insurance scheme, subsidies could be granted for screening and treatment of the disease.

Limitations and Strength of the Study

The main limitation of the study is that it was restricted to only one health facility, the Battor Catholic Hospital. Therefore, the findings of this study could not by generalised. However, the study also has a number of strengths. A major strength of this work is the use of qualitative approaches to provide in-depth knowledge on the barriers to cervical cancer screening and treatment in the district as well as experiences of patients. The study has also captured varied perspectives, and through the use of the biographical disruptive approaches, provided an understanding of how infected persons cope with debilitating diseases.

Recommendations for Further Research

It is recommended that future studies include more health facilities that provide screening and treatment for cervical cancer services in Ghana. This will increase knowledge on the subject in other health facilities and communities. Future studies should also be considered using quantitative methods to obtain a broader picture of barriers to screening and treatment and associated risk factors of the disease. Such an approach will provide quantitative data to substantiate the observations, which have emerged from the qualitative study.

The role of men in cervical cancer screening and treatment needs to be further explored and encouraged in academic studies. This is because as a genital cancer, the disease has an effect on both the sufferer and sexual partner in their sexual. In addition, most women rely on the support of male partners. Thus, further studies to determine the level of engagement of men in the efforts to control the disease would be useful.

The personal experiences or the biographical disruptions among partners of cervical cancer patients can also be considered for further research. This would help to unearth, in detail, what men go through when their wives are diagnosed of cervical cancer.

A further study on the role of faith healers in the uptake of cervical cancer screening and treatment is recommended given the belief in faith healing, as indicated by respondents of the study. This relates to the worldview of people and it needs to be understood and incorporated into health education programmes as well as screening and treatment practices.

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APPENDICES

Appendix 1: Informed Consent Form for Patients

Title: Barriers to Cervical Cancer Treatment among women in Ghana

Principal Investigator: Charity Binka

Address: University of Cape Coast.

The aim of this study is to assess perceptions and barriers to the screening and treatment of cervical cancer among women in Ghana. Therefore this research will focus on cervical patients, partners of cervical cancer patients, health professionals and women in the community. Participants for the study will be interviewed on one to one basis. However some of the newly diagnosed patients will be interviewed twice. This will be done because they will be followed up again to assess the factors that influenced them to either uptake or reject cervical cancer treatment. Similarly, an observation will also be done at health centre.

In order to identify the barriers to cervical cancer screening and treatment, I invite you to take part in this research project. If you accept, you will be required to take part in an interview, which will take about approximately 1:30 hours to 2 hours. If you do not wish to answer some of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place in Battor Hospital and no one else but the interviewer will be present. All information that will be given will be kept strictly confidential. I will summarize all the findings of those who participated in the survey. The interviewing is anonymous; you are not required to mention your name during the interview. No one will be able to identify you. There is no risk in participating in this study. Although you will not benefit directly from the study, the results of the study will enable us to institute screening interventions for eligible women.

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time without giving reasons. Your withdrawal will not affect how you will be treated in the hospital

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8:00 a.m and 4:30 p.m. through the landlines 0332135351/0289670793(4) or email address: irb@ucc.edu.gh **or the ERC administrator, Ms. Nita Coffie on** ***+233-0302681109/233-0302679323, or email: nitadzy@yahoo.com***

Part 2: Consent Declaration Form for Patients

I have heard/ read and understood the study that I have been invited to take part in. I have been given a written and verbal explanation and I have had the opportunity to ask questions and these have been answered to my satisfaction.

I understand that I have the right to withdraw from the study at any time and that my consent to take part would not alter my legal rights. I am also aware that all information collected is confidential to the researchers.

I understand that any information collected will be kept in a secured place for a period of 5 years before being destroyed.

I consent to taking part as a participant in this study.

Name of Participant……………………………………………………

Signature…………………………………………………………………

Date ………………………………………………………………………

Residential/Contact Address

Phone contact(s) *Home*…………………………… */ Work* ……………………….

Study Identification ……………………………………

***Witness to complete this section**

In my opinion consent was given freely and with understanding

Name of witness ………………………………………………………

Signature …………………………………………….

Date ……………………………………………

**The witness should not be a study investigator and should preferably be a person principally concerned for the patient's welfare, such as a relative. If a relative is not available a friend or hospital chaplain may substitute.*

Appendix 2: Informed Consent Form for Partners

Title: Barriers to Cervical Cancer Treatment among women in Ghana

Principal Investigator: Charity Binka

Address: University of Cape Coast.

The aim of this study is to assess perceptions and barriers to the screening and treatment of cervical cancer among women in Ghana. Therefore this research will focus on cervical patients, partners of cervical cancer patients, health professionals and women in the community. Participants for the study will be interviewed on one to one basis. However some of the newly diagnosed patients will be interviewed twice. This will be done because they will be followed up again to assess the factors that influenced them to either uptake or reject cervical cancer treatment. Similarly, an observation will also be done at health centre.

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I understand that any information collected will be kept in a secured place for a period of 5 years before being destroyed.

I consent to taking part as a participant in this study.

Name of Participant………………………………………………

Signature/Thumb print……………………………………………………………

Date ……………………………………………………………………

Residential/Contact Address

Phone contact(s) *Home*……………………… / *Work* ………………………

Study Identification ……………………………

***Witness to complete this section**

In my opinion consent was given freely and with understanding

Name of witness ………………………………………………

Signature/Thumb print ……………………………………………

Date ……………………………………………

**The witness should not be a study investigator and should preferably be a person principally concerned for the patient's welfare, such as a relative. If a relative is not available a friend or hospital chaplain may substitute.*

Appendix 3: Informed Consent Form for Women not Screened

Title: Barriers to Cervical Cancer Treatment among women in Ghana

Principal Investigator: Charity Binka

Address: University of Cape Coast.

The aim of this study is to assess perceptions and barriers to the screening and treatment of cervical cancer among women in Ghana. Therefore this research will focus on cervical patients, partners of cervical cancer patients, health professionals and women in the community. Participants for the study will be interviewed on one to one basis. However some of the newly diagnosed patients will be interviewed twice. This will be done because they will be followed up again to assess the factors that influenced them to either uptake or reject cervical cancer treatment. Similarly, an observation will also be done at health centre.

In order to identify the barriers to cervical cancer screening and treatment, I invite you to take part in this research project. If you accept, you will be required to take part in an interview, which will take about approximately 1:30 hours to 2 hours. If you do not wish to answer some of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place in Battor hospital and no one else but the interviewer will be present. All information that will be given will be kept strictly confidential. I will summarize all the findings of those who participated in the survey. The interviewing is anonymous; you are not required to mention your name during the interview. No one will be able to identify you. There is no risk in participating in this study. Although you will not benefit directly from the study, the results of the study will enable us to institute screening interventions for eligible women.

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time without giving reasons. Your withdrawal will not affect how you will be treated in the hospital

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8:00 a.m and 4:30 p.m. through the landlines 0332135351/0289670793(4) or email address: irb@ucc.edu.gh**or the ERC administrator, Ms. Nita Coffie on *+233-0302681109/233-0302679323, or email:* *nitadzy@yahoo.com***

Part 2: Consent Declaration Form for Women not Screened

I have heard/ read and understood the study that I have been invited to take part in. I have been given a written and verbal explanation and I have had the opportunity to ask questions and these have been answered to my satisfaction.

I understand that I have the right to withdraw from the study at any time and that my consent to take part would not alter my legal rights. I am also aware that all information collected is confidential to the researchers.

I understand that any information collected will be kept in a secured place for a period of 5 years before being destroyed.

I consent to taking part as a participant in this study.

Name of Participant……………………………………………………

Signature/Thumb print……………………………………………………………………

Date …………………………………………………………………………………

Residential/Contact Address

Phone contact(s) *Home*…………………………… */ Work* ………………………….

Study Identification …………………………………

***Witness to complete this section**

In my opinion consent was given freely and with understanding

Name of witness ………………………………………………………

Signature /Thumb print…………………………………………….

Date …………………………………………….

**The witness should not be a study investigator and should preferably be a person principally concerned for the patient's welfare, such as a relative. If a relative is not available a friend or hospital chaplain may substitute.*

Appendix 4: Informed Consent Form for Health Personnel

Title: Barriers to Cervical Cancer Treatment among women in Ghana

Principal Investigator: Charity Binka

Address: University of Cape Coast.

The aim of this study is to assess perceptions and barriers to the screening and treatment of cervical cancer among women in Ghana. Therefore this research will focus on cervical patients, partners of cervical cancer patients, health professionals and women in the community. Participants for the study will be interviewed on one to one basis. However some of the newly diagnosed patients will be interviewed twice. This will be done because they will be followed up again to assess the factors that influenced them to either uptake or reject cervical cancer treatment. Similarly, an observation will also be done at health centre.

In order to identify the barriers to cervical cancer screening and treatment, I invite you to take part in this research project. If you accept, you will be required to take part in an interview, which will take about approximately 1:30 hours to 2 hours. If you do not wish to answer some of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place in Battor hospital and no one else but the interviewer will be present. All information that will be given will be kept strictly confidential. I will summarize all the findings of those who participated in the survey. The interviewing is anonymous; you are not required to mention your name during the interview. No one will be able to identify you. There is no risk in participating in this study. Although you will not benefit directly from the study, the results of the study will enable us to institute screening interventions for eligible women.

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time without giving reasons. Your withdrawal will not affect how you will be treated in the hospital

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8:00 a.m and 4:30 p.m. through the landlines 0332135351/0289670793(4) or email address: irb@ucc.edu.gh **or the ERC administrator, Ms. Nita Coffie on *+233-0302681109/233-0302679323, or email: nitadzy@yahoo.com***

Part 2: Consent Declaration Form for Health Personnel

I have heard/ read and understood the study that I have been invited to take part in. I have been given a written and verbal explanation and I have had the opportunity to ask questions and these have been answered to my satisfaction.

I understand that I have the right to withdraw from the study at any time and that my consent to take part would not alter my legal rights. I am also aware that all information collected is confidential to the researchers.

I understand that any information collected will be kept in a secured place for a period of 5 years before being destroyed.

I consent to taking part as a participant in this study.

Name of Participant……………………………………………………

Signature/Thumb print…………………………………………………………………

Date ……………………………………………………………………………

Residential/Contact Address

Phone contact(s) *Home*………………………… / *Work* ……………………………

Study Identification ……………………………………

***Witness to complete this section**

In my opinion consent was given freely and with understanding

Name of witness ……………………………………………………

Signature/Thumb print ………………………………………………

Date ………………………………………………

**The witness should not be a study investigator and should preferably be a person principally concerned for the patient's welfare, such as a relative. If a relative is not available a friend or hospital chaplain may substitute.*

Appendix 5: Cervical Cancer Interview Guide for Patients

1. When did you first noticed something was wrong with you?
2. Describe how you were feeling?
3. What did you do about it?
4. Whom did you talk to when you suspected something was wrong and why did you tell that person?
5. When did you take the decision to go to the hospital?
6. Who asked you to do the test? What was the reason behind your visit?
7. Who performed the test and where was it done?
8. When did you get to know that what you were suffering from is cervical cancer?
9. Who broke the news to you about your condition?
10. How was the news delivered to you?
11. How did you receive the news?
12. Let us discuss what you are suffering from?
13. Before you got to know of your condition, what other cancer diseases were you aware of?
14. Tell us about your sexual life - age of first sexual intercourse, with or without protection, number of partners (practice of sex with or without protection)

Screening

15. How was your experience with the screening?
16. What actually was done during the screening?
17. For how long did you have to wait to be screened?
18. How long did the screening last?
19. How long did it take for you to get the results?

20. What where you required to buy or provide for the screening?

21. How much did you pay for the screening?

22. How much would you have wished to be charged?

23. What kind of support did you receive from – family, friends, work, church, mosque etc.?

24. What influenced you to accept the screening – How, why, when?

Diagnosis

25. What were you told about your cancer?
    a. Type and stage of cancer

26. Did you have additional tests/procedures?
    a. What were you told about these?

    b. How is the result of this test affecting you?

Treatment

27. What type of treatment were you given?

28. Describe your experience when you were put on treatment?

29. What influenced your decision to uptake the treatment- Faith etc.?

30. What sort of information were you giving concerning cancer/ treatment options?

Ending

Now lets us talk about your experience since you became aware that you have cervical cancer

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

32. Who have been supporting you-husband, children, friends, church mosque etc.?

33. What pieces of advice have you been given?

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

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

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

Appendix 6: Cervical Cancer Interview Guide for Partners

1. When did you first suspect that something was wrong with your partner? Why?

2. How did you discuss it with her?

3. What form of help did you seek with your partner? Medical or traditional?

4. What was your reaction when you were informed that your partner or wife had cervical cancer?

5. Why did you react that way?

6. What reservation do you have concerning the one who attends to your wife at the hospital?

7. What is the nature of the relationship with your wife since her diagnosis?

8. How has her situation affected the family?

9. What form of support have you been giving her (financial, cooking, accompanying her on hospital visits etc.)?

10. How many wives/ partners do you have apart from your wife?

11. What is your own understanding of cervical cancer?

12. What advise will you give to women and men about the disease?

13. What do you want the government to do concerning cervical cancer screening and treatment?

Appendix 7: Interview Guide for Women not Screened

1. Name the disease that affects women, which you know?

   What about cancer (that's if not mentioned)

2. What do you know about cervical cancer?

3. What do you think are the causes of cervical cancer?

4. Which of your family members has had cervical cancer or is suffering from the disease?

5. What information have you received from a doctor or healthcare provider about cervical cancer?

6. Which health facilities provide cervical cancer screening and treatment services?

7. Why haven't you gone for cervical cancer screening if you know the services exist in the community? (Possible reasons - too young, too old, not susceptible, has only one partner, fear of the unknown, fear of death, lack of knowledge etc.)

8. Tell us about your sexual life - age of first sexual intercourse, with or without protection, number of partners (practice of sex with or without protection)

9. What will it take to convince you to go for screening?

10. What will be your reaction in case you are diagnosed of having cervical cancer?

11. In case you are diagnosed of having cervical cancer after screening, whom will you share your cervical cancer status with and why?

Appendix 8: Interview Guide for Health Personnel

1. How do you get women to come for screening?
2. At what stage of the disease condition do they seek medical care?
3. What effect does reporting time has on treatment?
4. What forms of test do women go through when they report for screening?
5. How long do the tests take? How much do they cost?
6. How long does the treatment take?
7. What follow up procedures are available for defaulting patients?
8. What is your facility doing in general to ensure women do show up for screening?
9. How does the clinic time affect patients? (Staff number)
10. What will you say contributes to the women unwillingness to attend the clinic?
11. What do you want the government to do in order to promote women acceptance of cervical cancer treatment and screening

Appendix 9: Observational Guide for Health Institution, Personnel and Patients

1. Processes patients are taken through before treatment begins
    - How health personnel receive patients when they enter the health facility
    - How sitting arrangement is done
    - Nature of seats
    - How patients are welcomed
    - Preliminary activities
2. How screening and treatment of cervical cancer is done
    - Who performs the screening and treatment? Men or Women
    - The availability of screening and treatment equipment
    - Number and the type of health professionals involved in screening or treatment of a patient
    - Time involved in screening or treatment of cervical cancer
    - The venue where screening or treatment of cervical cancer is performed
    - The guidelines available for ensuring confidentiality
3. Patient
    - The behaviour of patients at the health facility
    - Interaction between patients and health personnel
    - Interaction among patients

Appendix 10: Focus Group Discussion Guide for Men

- What are some of the illnesses that affect women in your community?

  What about cancer (if not mentioned)?

- How did you get to know about cancer?
- What is your own understanding of cervical cancer?

  What is the local name for cancer?

- How can we prevent cervical cancer?

  What are the treatment options available for cervical cancer?

- What information have you received from a doctor or healthcare provider about cervical cancer?
- What reservation do you have concerning the one who attends to your wife at the hospital?
- What are some of the things that prevent women from undergoing cervical cancer screening and treatment?
- What advise will you give to women and men about the disease?
- How much would you wish to pay for services on cervical cancer screening and treatment?
- What do you want the government to do concerning cervical cancer screening and treatment?
- Why do men marry more than one wife/ have more than one partners?

Appendix 11: Focus Group Discussion Guide for Women

- What are some of the illnesses that affect women in your community? What about cancer if not mentioned?
- How did you get to know about cancer? What names do you have for cancer in this community?
- What about cervical cancer? (That's if she is able to mention cancer).
- What information have you received from a doctor or healthcare provider about cervical cancer?
- What is your own understanding of cervical cancer and what are the local names?
- How can we prevent cervical cancer? What are the treatment options?
- Which health facilities provide cervical cancer screening and treatment services?
- If you are aware of cervical cancer screening facility in your community why have you not gone for screening?
- How would you be convinced to go for screening?
- How much would you like to pay for a cervical cancer screening services?
- What are the things that will prevent you from undergoing cervical cancer screening and treatment?
- Since cervical cancer is a genital problem, what is your opinion on male doctors conducting the screening and testing of cervical cancer?
- What will be your reaction if you are told you have cervical cancer?
- If you are diagnosed of having cervical cancer after screening, whom will you inform your condition about and why?
- What are some of the challenges women with cervical cancer face in this community?
- What do you want the government to do to promote the uptake of cervical cancer screening and treatment in the country?

Appendix 12: Ethical approval

GHANA HEALTH SERVICE ETHICAL REVIEW COMMITTEE

In case of reply the
number and date of this
Letter should be quoted.

My Ref.: GHS-ERC 3
Your Ref. No.

Research & Development
Division Ghana Health Service
P.O. Box MB 190
Accra
Tel: +233-302-681109
Fax:+233-302-685424
Email: nitadzy@yahoo.com

20th February, 2013

Charity Binka
Department of Population and Health
Faculty of Social Sciences
University of Cape Coast

ETHICAL APPROVAL - ID NO: GHS-ERC: 11/01/14

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

"Barriers to cervical cancer screening and treatment in Rural Ghana"

This approval requires that you inform the Ethical Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethical Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within seven days verbally and fourteen days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED...
DR. CYNTHIA BANNERMAN
(GHS-ERC VICE-CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

Appendix 13: Institutional approval

NATIONAL CATHOLIC HEALTH SERVICE
(ARCHDIOCESE OF ACCRA)
Tel: +233 (0) 242 172284
Email: cathhbattor@yahoo.com

Catholic
Hospital Battor
P. O. Box 2
Battor via
Sogakofe
Volta Region
Ghana, West
Africa

Our Ref: ....

Your Ref: ....

23rd December 2013

THE HEAD OF DEPARTMENT
POPULATION AND HEALTH
UNIVERSITY OF CAPE COAST
UNIVERSITY POST OFFICE
CAPE COAST

Dear Sir,

RE: LETTER OF INTRODUCTION

Thank you vey much for introducing Mrs. Charity Binka to us with regard to her PhD research topic "Barriers to Cervical Cancer Screening and Treatment in Ghana".

Management would like to assure her that she would have our fullest cooperation when the time is due for her to undertake the research.

We look forward to meeting her.

Thank you very much.

Yours faithfully

CATHOLIC HOSPITAL

[illegible]

(PRIN. H/S ADMINISTRATOR)
FOR: MANAGEMENT

MOTTO: IN GOD IS OUR HELP AND OUR HEALTH